PERFORMING DIABETES : BALANCING BETWEEN 'PATIENTS' AND 'CARERS', BODIES AND PUMPS, SCOTLAND AND BEYOND

Griet Scheldeman

A Thesis Submitted for the Degree of PhD
at the
University of St Andrews

2006

PERFORMING DIABETES:

Balancing between 'Patients' and 'Carers', Bodies and Pumps, Scotland and Beyond

Marc Chagall - *Le Cirque* - 1967

Submitted by GRIET SCHELDEMAN
For the degree of Ph.D. in Social Anthropology
30th April 2006

The whole universe is thus presented as the arena for a permanent performance (...) everything dances: figures, objects, lines and colours.

A. Kaminsky (1989) *Chagall. The Russian years 1907-1922*. p. 331.

I, Griet Bernadette Leonie Scheldeman, hereby certify that this thesis, which is approximately 100,000 words in length, has been written by me, that it is the record of work carried out by me and that it has not been submitted in any previous application for a higher degree.

Date: 28 April 2006 Signature of candidate

I was admitted as a research student in September 1998 and as a candidate for the degree of Doctor of Philosophy in September 1999; the higher study for which this is a record was carried out in the University of St Andrews between 1999 and 2005.

Date: 28 April 2006 Signature of candidate:

I hereby certify that the candidate has fulfilled the conditions of the Resolution and Regulations appropriate for the degree of Doctor of Philosophy in the University of St Andrews and that the candidate is qualified to submit this thesis in application for that degree.

Date: 28 April 2006 Signature of supervisor: .....

In submitting this thesis to the University of St Andrews I wish access to it to be subject to the following conditions: for a period of 3 years from the date of submission, the thesis shall be withheld from use; I understand, however, that the title and abstract of the thesis will be published during this period of restricted access; and that after the expiry of this period the thesis will be made available for use in accordance with the regulations of the University Library for the time being in force, subject to any copyright in the work not being affected thereby, and a copy of the work may be made and supplied to any bona fide library or research worker.

Date: 28 April 2006 Signature of candidate:

Abstract

This study is about young people (age 11-16) with diabetes. Based on fieldwork in a paediatric diabetes centre in Scotland, it describes the ways diabetes is lived and *done* by young people, their health carers and insulin pumps. This enactment is contrasted with other ways of doing diabetes, as observed on short fieldwork trips to paediatric centres in Brussels, Gothenburg and Boston.

I explore the dynamics of diabetes care on two levels. I consider the interaction between health carers and patients. Comparative data from various paediatric centres make apparent how culturally and socially informed approaches towards adolescence, health and illness shape both care practices and patients' experiences, resulting in different medical outcomes. Concretely in the Scottish centre, a non-hierarchical holistic care approach by health carers emphasizing quality of life over health, informs the young people's perspective on diabetes. Being a free adolescent takes priority over managing diabetes, with the results of ill health and possible future complications.

The existing dynamics in this care framework change as a third actor enters the scene: the insulin pump, a pager-sized technological device continuously attached to the body. I explore the balancing act between young people and their pumps. As the adolescents actively engage with their pumps not to search for better health but rather to pursue a better quality of life, the guiding question becomes: how can a technological device for insulin injection double as a tool towards a desired identity and a different illness?

This work then, can be read as a concrete case study of how a uniform technological device is embedded and used in a specific cultural and social context. It can also be read as an argument for a re-orientation of paediatric diabetes care in the Scottish centre: care centred on collaboration and inclusion rather than focused on merely containing underlying conflict (between adults and adolescents, diabetes and life, health and quality of life). Centres in Brussels, Gothenburg and Boston, and the insulin pump concretely, show how collaboration can lead to good health *and* quality of life.
To leave us to wonder: is 'doing diabetes differently' synonymous with 'doing a different diabetes'?

Thanks

First and foremost to the young people with diabetes, and their families, in Millness, Brussels, and Gothenburg, who invited me in their homes and shared their stories. While some are prominently present in this work, many others peek behind all pages. Without their trust and kindness this dissertation would simply not have been.

To the Millness Paediatric diabetes team, who welcomed a probing anthropologist into their midst for a year. For their confidence and openness to discuss.

To the pharmaceutical insulin pump manufacturer, Disetronic, for a research grant funding this Ph.D.

To the Paediatric diabetes teams and their head paediatricians in Edinburgh, Glasgow, Harrogate, Brussels, Gothenburg, Yale and Boston, for their time, welcome and engagement.

To Alex Greene for introducing me in the diabetes world and showing me the tricks of the applied anthropology trade. She was my first guide in a surprising medical arena.

To Nigel Rapport for guiding me through exciting anthropological theory and the less exciting tribulations of writing a Ph.D. A wise advisor, he pointed me to readings, authors and others ways of writing, all the while leaving me space to explore, experiment and try again.

To staff and postgraduate students at the department of Social Anthropology at St Andrews University, in particular Tony Crook, Mark Harris, Kai Kresse and Joanna Overing, for their advice and friendship over the years.

To Jakob Meløe, for his exemplary way of thinking, writing, and being.

To friends at home in Belgium, Kathleen, Silvie, Frederik, Henri and Hideko, for putting PhD's and all that into a healthy perspective.

To Gonzalo, for mental stimulation, entertainment, and above all, keeping the faith.

And finally (the end as was the beginning), to my brother and sisters, Tomas and Anke, Tine, Joke, their combined eight children, and to my parents Rita and Claude, for normal life when at home and keeping me sane.

To my parents

Rita and Claude

for being (t)here

Contents

"... und alles, was man weiss, nicht bloss rauschen und brausen gehört hat, lässt sich in drei Worten sagen."

Kürnberger

" ... and all that we know, not just here and there heard about, can be said in three words."
(my translation)

Introduction

"*If my notebook is to be in order, I must, as it were, step straight out of doors from it — into life — and not have either to climb up into the light as if from a cellar or to jump down onto earth again from a higher level.*"

Wittgenstein[1]

On the wall above my desk, this quote was my motto during fieldwork and 'writing up' —"my notebook" being both fieldwork notebooks and this dissertation. I often cursed this choice, never having imagined that to opt for simplicity could prove so complicated. To "step straight out of doors, into life" meant no distant writing at my desk analysing what I had seen. Rather, I had to be inside, close to the people I wrote about, be one of them, one of many. This dissertation then is about people, and their lives.

It is a very 'personal account', centring on the *people* in this story: the subjects and the narrator. Since many objections can be raised against this approach, here I explain my reasons for doing so.

This work is part of my being-in-the-field, my relationship with the people, the topic, the place, the discourses, and the practices.[2] As such it is an instance of intersubjectivity. An intersubjectivity mainly coloured by a confusion that fuelled a continuous desire to understand. Since curiosity (or the more poetic 'sense of wonder') is the best teacher, I embraced the confusion. Initially as a way to get to know the field,

[1] Wittgenstein on how the thinking and the living need to meld, from one of his many personal notebooks (diaries) quoted in McGuiness 1988. *Wittgenstein: A Life (young Ludwig 1889-1921).* Berkeley: University of California Press (p. 57).

[2] I opted for disclosure in this introduction, choosing to mention many aspects of fieldwork and my reflections on these, instead of omitting them. For then this work would have been another cogwheel in the self-confirming/maintaining practice that some applied research is, and it would be untrue. Instead it

the propeller driving me forth, but gradually also as a way to see the world. For things —people, objects, ideas— are confused (from Latin con-fundere: pour together, mix up), they do not all fit in one ordered whole, instead they change, are interrelated, mutually constitutive. Thus when trying to make sense it is crucial to keep in mind that sense does not lie in an ultimate order, in pieces fitting, but rather in a sense of wonder at the complexity of it all and how it 'manages' to hang together. A bit like Kierkegaard's 'knowingly not knowing'. Thus confusion to start with and confusion to end. Otherwise we have taken a wrong turn.[3]

There, slightly more than Kürnberger's three words to say what I know. Even more words (some 100.000) follow to make the same point in a more illustrative way. So let me put these in their context. I start by describing the practice of fieldwork, how the project originated and, together with methodology and writing, developed over time. This narrative leads me to situate this piece of work on the (obligatory) anthropology shelves. After explaining what this work is *not*, I hope to make clear what it *is*, or at least, what I would like it to be.

1. 'Doing' Fieldwork: Intersubjectivity I

Although the main fieldwork site, the university hospital in the city of Millness, was only thirty minutes away by bus, fieldwork became a journey. During three years of research and writing, confusion was rife and productive: content, form and methodology underwent significant changes, best bundled under a 'change of perspective'. A change of perspective both as to 'from where' I was looking as to 'how', and 'what' I was looking at.

---

has to stand on the ground (no obscure scaffolding supporting it) and therefore here I recount its base, in detail.

[3] I realize this may sound like the ideal excuse: 'if all that follows does not make sense, it is meant to do so'. I will return to this towards the end of this introduction, when I explain what the thesis is about (in terms of anthropological theory). However, my quick reply here is that ending a research project with an explanatory model, might instead be a 'cop out' of the threatening chaos of the world.

1.1 Places, People and Methods

I begin with the origin of the research process, and the initial 'place from which' I was looking. The head diabetologist of the Paediatric diabetes team at Millness Hospital had designed a pilot project for insulin pump therapy with young people with diabetes. An insulin pump company would provide ten insulin pumps with consumables (replacement injection sets, syringes, tubes etc.) over the course of a year, thus enabling the centre to try out the practice of insulin pumps in young people. So far insulin pumps were almost not used with children in Britain, as the expensive pumps (£1000 for a pump plus a yearly £300 for consumables) are not funded by the NHS, unlike standard insulin therapy, which is free. A clinical evaluation, in the form of a Ph.D. research by a medical doctor working in the centre, would accompany the trial. The head paediatrician also secured pump company funding for a qualitative study in the form of a 3-year Ph.D. research grant by a social scientist. Thus I found myself in the medical world, not as an outsider having knocked on the door with my own project and after much to-ing and fro-ing, finally let in; but rather by invitation, to offer a non-medical perspective on a clinical trial. The difference is significant. It meant that my starting position was in the hospital. Both physically as the place home to professional health carers, visited by patients, and theoretically, in the form of applied medical anthropology. While the physical move out of the hospital and into people's homes was quite straightforward, the theoretical move from health carers' minds and clinical projects to the phenomenology of everyday lives proved more of a dilemma.[4] A more detailed description of the practice of fieldwork (below) will show how topic, methodology and writing style —in short my whole ethnographic approach— gradually became distanced from the epithets 'applied' and 'medical', towards just 'anthropology'.

Fieldwork started in the diabetes clinics at Millness Hospital. The Paediatric diabetes clinic was held every Monday afternoon in the colourful Paediatric outpatient

[4] This dilemma was purely down to me and the situation I found myself in: a trial project in a medical setting. How could I bypass the seriousness and instead look at just 'stories'? I stress that I was given absolute freedom by both the originators (the medical team) and the providers (the funding pump company) of the research grant. Although a research proposal had been drafted before I was involved, this was never enforced upon me. On the contrary, repeatedly asking what exactly I was supposed to research, I was told that it was completely up to me.

centre. Up to 15 toddlers, children and teenagers would be seen by the nurse and three paediatricians in one afternoon. They arrived with a (or both) parent(s) and would wait in the play area: parents chatted or read magazines (diabetes, lifestyle or gossip), while the children played with the available cuddly toys, dolls, prams, building blocks or computer games. The children would happily go and see the nurse to be weighed and measured, this would always be accompanied with praise (and shiny stickers as reward) from the nurse: 'would you take off your pretty boots for me?' 'How you've grown', 'You'll be a model'. The nurse noted the weight and height in the child's patient file and put it on a table in the hall, ready for the paediatrician to grab before inviting the child in to the consultation room. The children then went upstairs to the Adult Diabetes clinic to have a finger prick blood test done, came back with their machine-calibrated HbA1c level (a medium of their blood sugar levels over the last three months —concretely: a number, anything ranging from 5.6 to 13, on a piece of paper)— and waited to be called in by the paediatrician.

I would hang around in the patients' waiting area, or in the health carers' supply cupboard-cum-coffee room, trying to strike an impossible balance between unobtrusiveness, discretion, sympathy, curiosity and dedication to 'doing my job'. Invisibility does not combine well with 'wanting to be there to know all that is happening'. Before starting fieldwork I had been informed (and warned) by anthropologist Dr. Alex Greene, who had previously conducted research in the same team, that health carers are so busy and stretched for time, wanting to do their jobs as well as possible, that they have no time for questions.[5] I should thus not take it personally if they were stroppy or just rushed. I should sit, wait, be available and take the opportunity to talk whenever it was convenient for them, like in the coffee room, or in chats in between. This comment helped me in not taking things personally, but at the same time it made me very conscious of me being there and interfering with the health carers' job, so I treaded carefully. Thus in the hospital, I, like all mortals entering its sliding doors, was on hospital time. Hospital time is different from outside-world time

[5] Alex Greene (2000) studied the conceptualizations of diabetes by young people and health carers, focusing in particular on the relationships between young people and their health carers in Scotland. My entry into the field (both of diabetes and concretely the Millness team) was greatly facilitated by her pioneering role. As a researcher she remained connected to the Paediatric team, and she will briefly feature again further in this work (Chapter 7). I will also refer to some of her findings in later chapters (the Context chapter and Chapter 5), acknowledging her in-depth research without dwelling on it, since I opted for a different analytical and theoretical approach in this work.

and is run by health care professionals.[6] I noticed this at my first coffee room attendance, where all doctors and nurses were happily chatting, I presumed waiting for late patients, only to find out that there were five patients waiting in the waiting area and the staff was just taking a break.[7] Thus during fieldwork, I was on time's side, or time was on my side, as I noticed months later when I came in to have my insulin pump fitted. As a 'patient' I 'was kept' waiting, my 12 o'clock appointment became 1 before I 'was seen' by the nurse.

During my visits to the hospital, I hung around in the health carers' coffee room, asking whether I could 'sit in' with one of them in their consultation room that afternoon, whether there were any patients on pumps coming in, whether they thought there was any patient in particular who would be happy to talk to me. I would then settle with one paediatrician in one room, becoming part of the furniture, seeing all patients she saw that afternoon. In case the paediatrician expected a 'difficult' consultation (difficult relating to psychological or family problems), she would ask me to leave. I would also move to another room in case there was a present or future pump patient being seen at the time by another paediatrician, whom they thought I should meet. As the teenagers and parents entered the consultation room, the paediatrician would introduce me with 'this is Griet, she is an anthropologist and she is doing research with us'. Sometimes this would be followed by the question whether they minded if I sat in, sometimes not. People would just nod and did not seem to mind. I explain this by the fact that Millness is a university teaching hospital, doctors and nurses learn by observing, sitting in, patients must be used to it; also the diabetes consultation did not involve either a physical examination, or a sensitive and personal conversation —again, when it did, I left the room. My, or any, additional presence in the consultation room was taken as normal.[8] I was either ignored and made invisible, or people addressed me as an extra person in the room to comment to, mainly to praise the team with extra

---

[6] Is it a detail that all clocks I saw (and after a while, I made a point of checking them) were either late, ahead or not ticking?

[7] It is surprising how fast one, in this case I, gets sucked into this and floats happily along. If I am in hospital all day doing my job, then people coming to see me can wait. I stay put, I have my time, and patients come and go.

[8] Only once, in a total of around 100 consultations observed, did a parent comment on my presence. Nurse Sally had introduced me to the patient, a 15-year-old boy who had said he did not mind I sat in. When Dad joined us a bit later, he suddenly interrupted Sally, saying: 'who's that?' pointing his chin in my direction. Both Sally and I hurried to explain who I was and whether he minded if I stayed; I offered to leave. Cutting short our explanation, Dad replied: 'No, just nice being told'. His reaction is normal; I am mainly surprised he was the only one who did question my presence. Since everyone was always fine with me sitting in, after a year you tend to leave out the question.

compliments: 'We all love Sally so much, honestly, and I'm not just saying that 'cause you are here'.[9] The consultation would last from 10 up to 30 minutes. A fixed item on the agenda would be the HbA1c: the blood finger prick which gives an idea of the blood sugar control over the last three months, the benchmark against which to evaluate whether diabetes management is going well or not, and an indication to discuss changes in insulin dose or injection frequency. The paediatrician would check whether parents or patient had any queries or problems, or whether they wanted to talk to the dietician or psychologist, who would also be present at the clinic. If all went well, they arranged to come back in three months time.

When the paediatrician had alerted me beforehand that 'this boy/girl would be good to talk to' (usually because they were talkative or did not have huge issues with diabetes), I would follow them on their way out and introduce myself. I would explain my research, how I wanted to understand what it was like for young people to have diabetes, as I knew nothing about it. I was not concerned with the medical issues, but what it meant to live with diabetes everyday. Would they be all right to talk to me about it? Some said no, they did not want to. Many said yes, with the words 'I don't mind'. We exchanged phone numbers and agreed I would call them to find out when and where it suited them to meet. One afternoon in clinic would give me an average bounty of four names and numbers.

When all patients and families had gone home, the health carers' team gathered for the after-clinic meeting. Each paediatrician, usually two or three, would briefly discuss every patient she had seen that afternoon, 'Simon is doing just fine', 'Mum is insecure about insulin or diet', 'tension between Dad and 14-year-old Malcolm'. The team, nurses, dietician, psychologist and paediatricians, would debate whether a home visit was required by the diabetes specialist nurse, or whether the dietician or psychologist should arrange a follow up visit. As the case load is shared, meaning that Malcolm who today was seen by Dr. Caroline may at his next visit in three months time be seen by Dr. John, this discussion and the updating of patient files are important to ensure continuity in care. To me these meetings were extremely informative. After being a fly-on-the-chair in the consultation, now I heard the doctor's interpretation of it. The often-animated discussion with other team members (about that patient's attitude,

[9] Again, only once —to show how exceptions make the rule— did a young patient come up to me, hand stretched out, to say hello. This articulate and polite 15-year-old was William, a pump patient who will feature extensively in Part Two.

that mum's worries, etc.), proved an essential addition to the 'standardized' consultation. This is where the team members came to life, as did their concerns and approach to care.

While the ten young people on insulin pumps came to the Paediatric clinic, since Dr. John was the head of the trial project, I also attended the Young Adult (age 16 to 22) clinic.[10] This clinic took place monthly on late Wednesday afternoons in the adult diabetes clinic. Although the Young Adult clinic followed a similar scenario, the atmosphere (both of location and interaction) was more serious and less personal.[11] Compared to the crèche- like Paediatric clinic (even though some children were 16 or older), the Adult clinic's waiting area resembled a hotel corridor: wallpaper and paintings with copper lamp fittings on the walls. Paediatricians shared the clinic with Adult physicians, the latter used to an extensive patient caseload, shorter consultation times and thus less possibility for personal contact. Adult physicians have a more detached and formal attitude towards the young people they do not yet know, and probably will never get to know as well as the paediatricians who have seen these young people grow up over the years.[12] Concretely, while in the Paediatric clinic we (doctors, nurses and myself) were all smiles, caring and friendly during consultations, the Young Adult clinic consultations (depending on both patient and doctor) were more business-like check up visits, discussing numbers (amount of injections, times, test results). While in the Paediatric clinic the children and young people were the stars (this clinic was for them, they shun or were troubled and sad), in the Young Adult clinic the professionals were the protagonists running the show. Thus before a young person would enter the consultation room, the physician would take the patient's file and give me a brief synopsis of the next 'case' about to come in. While very helpful to me, at the same time I was uncomfortable, feeling I should not know these intimate details of a person I had not even met. Paediatricians did not do this, only sometimes after the consultation, when I had seen the patient and parents and heard their story, the paediatrician would turn to me and we would share our worry or endearment. Similarly,

[10] The clinic's age category (16 –22) was flexible, the move to the adult clinic usually coincided with leaving full-time education, thus earlier for school-leavers than for university students.
[11] Another difference with the Paediatric clinic is that young adults would also undergo a yearly screening: eye tests, test for micro albumen in urine etc., to monitor diabetes complications.
[12] Adult physicians spend most of their days dealing with older patients with diabetes complications. The abundance of adults with diabetes means that the physicians see most patients for an average of 10 minutes and that there is often no continuity nor any profound doctor-patient relationship.

the caring and funny Paediatric clinic meeting (is it significant that the all-female team was headed by one man, Dr. John?) was matched by the Young Adult team meeting featuring the three (alpha) male doctors vying for the best joke, discussing the patients, for the all female (nurses) 'audience' (though they said their bit too).

Apart from following both clinics for a year, fieldwork at the hospital also included attending Paediatric team meetings —where the team discussed care strategies and organizational issues— and evening seminars for parents informing them on new developments and psychological issues in diabetes care. After four months of 'being there', by now familiar with the team, and the team with me, I began to ask individual team members for an 'interview'. Interview is a wrong term for these deliberately unstructured conversations.[13] I wanted to find out what mattered to the team members, so as to pick up my research focus from that. Thus while the topic was adolescence and diabetes, and with a few general questions in the back of my mind, instead of a question and answer session, we had a chat. They would tell me their issues and concerns, I would tell them mine, what I had noticed they did, and my questions or surprise at that. Together we would wonder and think hypothetically. A shared trying to make sense.[14]

Thus in the hospital, I was an 'outsider' part of the diabetes team. The team endured me observing them; they took me on board, gave me their time and patience and did the effort of engaging in conversations with me, answering my questions. And here is another confusion. As mentioned before, I had been made aware of the fact that health carers were always pressed for time, and that they were being generous in allowing me to be there and even taking time to explain things to me. I understood and appreciated this, always keeping it in the back of my mind when in hospital. However, I had been recruited by the team to do this job. I did not feel I had invaded them, they had asked me to come and study. So while being careful not to interfere, on the other hand I felt I owed them a good job, I had to ask questions, I had to take the initiative. How else could I do what they had wanted me to do? While difficult, I could have struck a

[13] I never recorded any interview or event on tape, as I felt that would completely change the occasion. I turned up everywhere with my eternal notebook —'Griet, always scribbling things down'— and got quite skilled in jotting things down while at the same time following the conversation and thinking of themes to bring up. A one-hour session would leave me exhausted.

[14] A frequent reaction to my thoughts was: 'that's a good question', 'I never thought of that' and we would pursue that track together. Thus rather than 'question – answer' format, we would question and

balance. But the situation was complicated even more by (what I privately called) 'sabotage' by one team member, a protagonist in the project. As an exasperated fieldwork diary excerpt illustrates:

'*As Sheila is the single pump nurse, the main health carer involved in the project, I do not understand her reluctance to share basic data like names and contact numbers of the ten pump patients with me. I am supposed to study them, how can I without knowing who they are, without being able to contact them? Further reluctance in talking to me and taking me along on her home visits. Understandable reasons are privacy, protecting patients and having to do a job. Do 'forgetting' to inform me about a visit to a patient's home, 'accidentally' giving me the wrong date for a home visit, picking me up from a service station 1,5 hours late, on the way to a home visit, all fit under this banner? If they do not want me to study this, to be there, to observe, then why this grant?*'

Apart from donning velvet gloves every time I spoke to Sheila, over time I learned to see her attitude as individual, not the team's. Maybe she did not want to be lumbered with me, maybe she did not want anyone impinging on her 'freedom', as she was the one running this show, so far without many (professional) observers.[15] After three months I did get the names and numbers of the patients, and managed to accompany Sheila on some home visits, but I did not get a full picture of 'pump therapy' in Millness. For, as ever in this fieldwork, there was the 'sensitivity' and 'confidentiality' issue, I was careful not to press any demands, gathering pebbles instead of studying the whole rock.[16] My data on the pump project is thus partial, not only for so many missed moments, but also because what I took as the whole team's approach to insulin pump

---

think together. This helped me to probe their thoughts and get a good feeling of what mattered to them, what kept coming back, what were mere conventions and what they felt strongly about.

[15] Over the next months, as I followed Sheila on her home visits to the patients introducing young people to pumps, I was struck by the short time of education (three hours to start life with a 'lifesaving' permanent electronic device) and by the relaxed messages given with it. Where were the warnings, the 'never do this', 'it is important to always do that', 'if this happens then check'? The safety regulations, that are so present in other areas in this country —from advice on food packages to notices in railway stations to yellow cones on wet floors (caring or waving responsibility?). I kept assuming that the families had had other meetings and information packs, Sheila had 'forgotten' to mention to me. Only after four months, when I was sure that I had attended all contacts, meetings, clinic visits and Sheila's home visits with new pump patient William, I realized that what I had assumed to have missed, had simply never been. I am worried and alarmed. I feel the pump can be a time bomb if patients are not instructed and warned about the risks. Am I exaggerating? This is my first ever experience with insulin pump therapy. When later I visit other hospitals in Scotland, in England, in the US and Sweden, my apprehension gets confirmed: the pump is a serious implement, initiates need to be instructed fully and in detail about its use and risks. So was Sheila not happy with my presence because she felt she was not doing all she could?

[16] After the pump project Sheila, who had been a nurse for 20 years, left the NHS to become an educator-cum-sales rep for a medical company.

therapy, was mainly (and I realized this after some months only) how one nurse, almost independently, practiced it.

While Millness was the central fieldwork site, I also ventured briefly into the larger diabetes world. Twice the Millness team took me along to *the* main international paediatric diabetes conference, organized by ISPAD (International Society for Paediatric and Adolescent Diabetes) at Siena (2002) and St Malo (2003). Three days of seminars and workshops by the main medical players introduced me to the global scene of diabetes care.

To be better able to place the Millness Paediatric diabetes team and pump centre, to have a backdrop for the scene —as it was a new world to me— I gradually drew larger circles around it, compassing Scotland, England, Europe and North America. Thus I visited Paediatric and Young Adult diabetes centres in Glasgow (Yorkhill and Sick Children), Edinburgh (Sick Children), Harrogate, and abroad in Belgium (Brussels), Sweden (Gothenburg) and North America (Yale and Boston).[17] During these mini fieldworks, ranging from one to three- day visits, I sat in at clinic consultations and 'interviewed' the head paediatrician and the diabetes nurse of the centre. By then, from the conversation with the Millness team, I had found the themes I wished to focus on. These visits were enlightening. Up to then, a novice to diabetes, all I had observed in Millness seemed 'absolute'. Now, talking to other teams, and seeing other ways, priorities and philosophies, the world opened up, and I came home. I had found a space for my worries, surprise and queries. Though I had never met before any of the professionals I spoke to, we shared common ground, and it felt like a long-suspended conversation finally happened. The question marks in my head, writhing around each other for months, came out and dissolved. While the data gathered outside Millness features explicitly in the comparative chapters 3 and 4 (Belgium) and chapter 9 (Boston and Gothenburg), implicitly the observations and conversations from elsewhere are omnipresent. They also strengthened my belief in the importance to portray 'how diabetes is done' at the Millness centre, as it is quite specific.

[17] I visited the Yale and Boston clinics together with Sheila and Veronica, a junior paediatrician diabetologist of the Millness team.

Introduced so far are the professionals in this story, the health carers doing their jobs, 'doing' diabetes. Now I turn to the non-professional (though far from less 'expert') young people also 'doing' diabetes, every day.[18] Thus I move from the hospital to people's homes. [19]

Considering the initial difficult access to the pump patients, I resolved to talk to any young person with diabetes who wanted to talk to me. This way I got to know life-with-diabetes. In total I conducted around 30 interviews with young people (aged 11 to 22) attending the Millness clinic. We spoke about life before and with diabetes, what they minded about it, what they liked, if they thought they'd be a different person without it, how it was in the family, at school, with friends. What they thought of the team at Millness. A question they found difficult but took to heart was how they thought the team should approach teenagers. What would be their ideal scenario? I was thus armed with what mattered to young people in life with diabetes, their difficulties, worries, feelings, before I met the patients on pumps. I met nine patients on pumps, plus four who had worn the pump for several months and quit. Four pump patients I followed closely over a year, repeatedly visiting them at home to talk to them, their parents and in some cases their friends. The style of these conversations will also become apparent in the ethnography that follows. Again, as with the health carers, it was rather conversing, looking for answers, sharing thoughts together, instead of questions and answers. Hypothetical talk, 'what if', and 'imagine', which proved extremely suited to find out what mattered to people. 'As if' talk giving a kind of freedom, a space for deep-seated wishes and worries.

After meeting the young people in the clinic consultation, I would call them to ask when and where it would best suit them to meet. Almost all asked me to come to their house, some older ones (aged 15 to 18) preferred to meet me in a café. At the house some mothers (occasionally fathers) asked if they could join us —I always replied it was up to their child, what they felt comfortable with— others on the contrary

[18] The next chapter, sketching the context, expands on the present powerful concept in the NHS of 'The Expert Patient'. I am wary of constructing two sides here: professionals in the hospital versus young people at home, and thus to fall in a similar dualist trap of much of medical anthropology, both of which I feel strongly about (and I struggle to compass both dualism and medical anthropology), and to which I will come back in Chapter 6.

[19] This was not a move located in time, as hospital and home fieldwork happened parallel over the year. I would initially meet the young people in the hospital, then visit them at their home, then again see them in the hospital. I would mix worlds like they did. —Though in the hospital I was more 'at home' than they were, even though they had a genuine reason to be there, while I felt like an impostor.

said 'I don't need to be there do I, it's Ailsa's diabetes' and would disappear to the kitchen. From then on it was more or less in the young person's hands. They would decide where we would go and how the conversation would evolve. Thus no tape recorder, no list with questions, no structure. I would explain I was interested to know what living with diabetes is, and what it means they have to or cannot do. We would sit on the sofa in the living room. Whoever came into the room, mothers, siblings, fathers, would add comments, throw in a joke and leave again, or sit down and join in the conversation. Thus often it became a conversation between mother and son/daughter, and myself listening, asking a further question and they both would tell their side of the story. In some cases, the mother would thank me afterwards and say that she never really discussed these things with her son/daughter —diabetes would usually be a point of argument or short outbursts, not sitting down and talk about what it meant to live with it— and that this conversation had been a first. I thus sometimes felt guilty as people saw me as a psychologist, and moreover, because talking about life with diabetes and finally discussing topics usually kept covered could be emotional for all involved. Tears and 'running off' happened twice, but ended in good spirits.[20]

While at the hospital I could spend my days hanging around observing health care professionals interacting with their colleagues, with patients, doing their jobs, being doctors, but also joking during breaks, relaxing and having fun during evenings at conferences —with the young people I could not do this. Although I would have liked to 'live' with a pump patient for a week, follow her to school everyday, to sports and parties, see those details of life with a pump which never come up in conversation, this was out of the question.[21] The only opportunity I had to spend time with young people with diabetes (and do classical fieldwork by being there and participatingly observe) was at two diabetes camps. At the beginning of fieldwork, I attended a camp, an outdoors weekend organized by the Millness team for the 11- to 16-year-olds of their clinic. I was thrown in at the deep end, diabetes in Scotland in full swing. Thus chocolate, biscuits and coke all around. Nightly raids on the staff's emergency rations

[20] It struck me that after very personal conversations at their home, in which I felt we had built up an intimate rapport, when next I would meet this person and parent by chance, in clinic consultations, they did not seem to recognize me. Not wanting to impose, I never checked with them, so I do not know whether it was shyness, or rather strictly dividing home from hospital, so that either indeed I was a different person or they did not want to bring what was discussed at home in the consultation room.

[21] I recall the difficult access, the sensitivity and privacy issue. However, this would be a next step, to make a documentary of a day in the life of these young people.

(in case of hypos) and in the morning the telltale wrappers between the chalets. Rowdy and unruly behaviour by the 16-year-olds, tentative imitations by the 12-year-olds. And of course abseiling, rowing, quad biking, fun and games, new friends. I finished fieldwork with another diabetes camp: a two-week outdoor activity camp bringing 20 Young Adults (aged 16 to 23) from all over Britain to a log cabin at a Scottish loch. An idyllic setting for a magical experience.[22] On this occasion I could hang around, be there, see whatever happened at any time of the day or night, and mainly see young people 'be' and 'do' instead of talking about what they did or felt.

By now it has become clear that my methodology was far from methodological: no system, no rigor, no representative sample. It was just happenstance, I met who I could and who wanted to talk. I hope that meets the *ethical considerations* on research. Is anthropological fieldwork (in the Western world) ethical when the people we work with, talk to, think and write about know that (and why) we are doing so, and are in full capacity to refrain from being researched? Liking to think of myself as a respectful moral agent, I pondered for months over the ethics of my 'method' —the pinnacle of sophistication: asking people whether I could come to see them for a chat. When asking young people for a chat, I took great care in making clear I was not linked to the medical team, that they had no obligation whatsoever to talk to me, that they were free to say no. Hoping to take away any power imbalances or making people feel 'coerced' into talking to me. Almost all conversations with young people were held in the presence of one or both of their parents, or not, if they wished so. I think the method was not unethical. For anthropological fieldwork. However, any research in the medical field is now wholly dependent on 'ethical consent' forms and strict regulations. But then I mentioned before that this present research 'grew' away from 'medical' and 'applied'.

1.2 (Change of) Perspective

1.2.1 Positionality

Everything described so far has shaped my positionality, which in turn shaped the perspective I take in this work. While I argue my theoretical position in section 3 of this introduction, here I mention two concrete aspects. One obvious fact is that I trained as a

[22] See Appendix 1 'Pinewood Camp' for an ethnographic account of this camp.

cultural and social anthropologist; I thus not only studied and interpreted events and conversations from a certain slant, but also, by doing so, interfered in what was happening. Another aspect is my 'Belgianness', which I chose not to bracket but instead made into a methodological tool, for the following reason. And here I need to make a brief excursion in diabetes medicine.

In 1993 the famous Diabetes Control and Complications Trial (DCCT) provided definite evidence that childhood diabetes 'was not for free' (Greene 1996: 563); Blood sugar control in younger years has implications later in life. The study showed that intensive management with the goal of keeping the blood sugar levels close to normal did have a positive effect on long-term complications of micro- and macro- vascular damage (with dramatic consequences such as blindness or amputation). This evidence made 'tight control' (keeping blood sugar levels as low as possible), a mandatory goal for diabetes care in young people. Eight years later, in 2001, a study comparing blood sugar control between 22 Paediatric centres across Europe and North America still found significant differences.[23] Millness featured at the bottom of the league: the blood sugar levels of their young patients were significantly higher than in other centres. The centre at the top of the league, showing the best results, was the diabetes centre of Dr. Dumoulin, a Belgian paediatrician in Brussels. I was first made aware of Dr. Dumoulin by the Millness team: "Oh, you're from Belgium, then you must know Dr. Dumoulin?" I had never heard of him. As they told me about his amazing results with diabetes management in young people, "impossible, he must be tampering with his data", my curiosity grew. While they urged me to try to talk to him and find out 'how he did it' I began to wonder whether there was indeed anything to find out. Or would I find what I expected of diabetes care, which differed from what I observed daily in Millness and which did not stop surprising me? —In other words, while Millness carers kept asking 'how does he do it?', before meeting Dumoulin I could think of all the things he might do differently from Millness and which would thus lead to better results. So many things I witnessed at Millness made me think: why? With always the same mantra in my head, wanting to shout out: "but these kids have diabetes!"

I made my surprise and amazement into a methodology. It pushed me along, informing my conversations with both health carers and young people. While being an

[23] The Hvidøre Study (1997) and follow-up study (2001) will be discussed further in the next Context chapter (Mortensen et al 1997 and Danne et al 2001).

outsider in the medical or everyday world of diabetes, I had, by nationality, a way into a comparative research. And while I did not want this whole work to be comparative I did conduct one week of comparative fieldwork at Dumoulin's centre. An extensive half-day interview with him and four days visiting his adolescent patients at their homes. Once I had spoken to Dumoulin and his young patients, I fed this information back into my conversations with the young people at Millness 'In Belgium there is this doctor who... how would you feel about that?' 'His patients said that....', and asked for their opinion on this.

While a discrepancy in medical results (blood sugar levels) formed the impetus for a 'comparative' look and continuously informed my perspective in fieldwork, I turned away from an applied medical approach.[24]

1.2.2 Applied Medical Anthropology[25]

Although this research project started as applied medical anthropology, it did not end this way. In the next section (2) I engage briefly with the medical anthropology literature and point out some theoretical reasons for moving away from applied work, but first I discuss the concrete reasons as 'lived' during fieldwork.[26]

While the project originated to study 'health beliefs' of health carers and young people on insulin pumps, I soon pulled it open to include the whole paediatric diabetes setting. As insulin pump therapy was heavily situated in the broader practice of diabetes care, a clear understanding of the latter was essential to situate the former. During the first weeks of research, spent reading up on clinical and psychosocial studies in diabetes and talking to health carers, the following things became apparent and added up.

- Good blood sugar results are indicative of good health later in life (less diabetes related complications).

---

[24] Another conundrum in this work, as it is of course the question whether I can combine one with the other.

[25] In the *Encyclopaedia of Cultural Anthropology* (Holt 1996: 759), Mc Elroy describes applied medical anthropology as dealing with "... intervention, prevention and policy issues, analyz[ing] the socio-economic forces and power divisions that influence access to care". The *Dictionary of Anthropology* (Blackwell 1997: 316) describes applied medical anthropologists as "interested in making cultural knowledge useful to the aims of medical practitioners".

[26] I stress that of course any anthropological research is applied, as it is about people and life. With 'applied' here I mean a specific research approach and finished product.

- Comparative international research put Millness at the bottom of the league in blood sugar results.
- The Millness team called (like many other teams and literature) adolescents with diabetes 'a challenge', and a continuous concern was how to reach adolescents and give them good care.

Here was a question: how to approach young people so they get good blood sugar results? There might be an answer, or at least some answers, as studies showed that other teams did get good results. So some ways of care must be more efficient than others. The answers are important: there are lives at stake, an explanation could effect changes in care and lead to better results. One path to the answer might be to talk to Dumoulin and other centres with good results and to study how they 'did' care. Especially since the clinical studies concluded that the different results were not explained by difference in resources but must lie in deployment of these resources, in the philosophy of care.

I had found my topic. I would research pump therapy, but in the broader context of adolescent diabetes care. My main concern was young peoples' health, or rather their lives, now and later. If I could find out the views of both health carers and young people on diabetes care, both in Millness and elsewhere, I would feed back some findings to the Millness team. As an in-between I could talk to both health carers and patients 'freely', question their assumptions and maybe give them another picture of diabetes in Millness, parallel to the one they painted every day. I did so in practice during fieldwork (action research), as I thought it was my job and because I found this issue important. However, for my research approach, confusion set in again in many guises. Psychosocial research on adolescents with diabetes abounded, what could I do that had not yet been done? What kind of 'results' were expected from my research? Did I have to be exhaustive, write a conclusive report, and come up with recommendations? As during the first year of fieldwork, this was the literature (medical research) I read, the conversations I was engaged in, the events (medical conferences) and places (hospitals) I resided in, this was the direction I was led in. Thus I fed back my findings and thoughts through comments and questions (never in an official talk) to the Millness

health carers, both individually and in team meetings.[27] I gave PowerPoint presentations to medical audiences (at PUMP-IT, an insulin pump conference held in Birmingham 2002 and at the University of Bradford 2003) and presented posters at the IDF (International Diabetes Foundation, Paris 2003) and ISPAD (International Society for Paediatric and Adolescent Diabetes, St Malo 2003) conferences. Thus my first analytical thinking on the topic focused on how to tell a medical audience something relevant.

Then my interest waned and took my drive with it. I had said what I had to say, with a concrete example I illustrated how a certain (culturally and socially informed) approach to care led to certain health outcomes. And thus how health outcomes could be influenced positively. This was my message to the medical professionals. But I found that those who engaged with it were already convinced practitioners of it.[28] While the ones I meant to reach, the Millness team, saw things in a different light.[29] Again, not understanding the point of a research whose initiators did not ask for findings, I decided to take my own direction and go for what I really wanted to do, some kind of anthropology. As I deemed the above message not very relevant to anthropologists, I did not pursue the applied research in writing.[30]

The story of doing fieldwork has, I trust, made clear how the research was an organic process: no strict method, no numbers, surveys or questionnaires, no corroboration, no starting with a plan and ending up with an encompassing model. Rather, this research, the data and the written account are partial —not 'incomplete' which would assume a complete version of them. Thus confusion to start with: in a change of topic and perspective.

---

[27] I had expected to be asked to give a presentation to the team on my research, to tell my side of the story. This never happened. I do not know whether they did not want to take up my time or pressure me, or whether they felt they already knew my stance from my frequent questions and comments.

[28] Specifically, most health carers in the centres I visited in Scotland and abroad, the ones where I came 'home'.

[29] When at team meetings I would mention (non-confidential) things I heard from the young people, for example 'they are not aware of complications' a doctor would reply 'no no, I can't believe that, they know' and the matter would be closed.

[30] As I noticed when giving papers to anthropologist audiences, they were not interested in the medical 'facts', they wanted to hear ethnography and theory, something interesting and creative.

2. What This Work Is *Not*

The topic of this dissertation may have led readers to expect —like I did initially myself— that it belongs in certain subfields in anthropology, more precisely the anthropology of childhood and medical anthropology.[31] While this work does indeed discuss young people and diabetes, I do not wish to situate it in either of the above. Before describing which 'anthropological stream' I did eventually jump into, I need to briefly mention the ones I passed on the way.[32]

2.1 Anthropology of Childhood[33]

In her 1973 article 'Can there be an anthropology of children?', Caroline Hardman makes a case for children as "people to be studied in their own right and not just as receptacles of adult teaching" (1973: 87). Twenty years on in 1992, Jonathan Benthall reporting in the editorial of *Anthropology Today* on a RAI seminar on "children as social agents", repeats this stance: "refusing to see children as empty buckets filling up with culture" (1992: 1). Still ten years later I could sum up (British) anthropology/sociology of childhood with a similar phrase. Of course stance and terminology are more sophisticated. Sociologist Jenks (1996) stresses the discursive properties of childhood, promoting to see childhood as a social construct. He reacts against the standard sociological view of childhood as a natural phenomenon, that seeing the child as 'not-yet-an-adult' stresses a child's incompleteness, its 'becoming' (Jenks: 10, also James et al 1998: 207). Instead Jenks proclaims a conception of the child as 'potential', an agent of change, and thus as 'being' something in its own right (Jenks: 46). Allison James (2002) reacts against seeing 'childhood' as a singular phenomenon, claiming instead it differs across culture, age and gender as children actively negotiate their own identities (James: 143-144). Not surprisingly then, in their co-authored *Theorizing Childhood*, James, Jenks and Prout (1998) promote a child- and agency- centred approach, focusing on a particular and local instead of a universal

[31] Though the more politically correct term is 'anthropology of health and illness', I do use 'medical anthropology' here, as it refers specifically to Western biomedicine.
[32] 'Briefly', thus not doing justice to the richness and variations of the two fields.
[33] For a comprehensive introduction to prominent British authors (sociologists and anthropologists) on childhood see Jenks 1996, James, Jenks and Prout 1998 and Hutchby & Moran-Ellis 1998. The term

global view of childhood, by firmly establishing the autonomy of the cultural world of children. The title of Hutchby and Moran-Ellis' edited volume (1998) *Children and Social Competence: Arenas of Action* heralds the same message: children are 'competent social agents', not, as often (mistakenly) believed, 'apprentice versions of adults' (1998:1). Have we come full circle? All authors reject one universal 'childhood' for an endless diversity of particular childhoods. Since 'childhood' is not only created by society and institutions impinging on passive children, but is also enacted and created by children, children and their cultural worlds merit their own anthropological study.

My point is that today this theoretical focus has become redundant. Of course children are competent social actors and people to be studied in their own right. Hence I do not see the need for this subfield of anthropology of children.[34] Thus in this work I will not further engage with 'anthropologies of childhood', as what they purport I take for granted.[35]

Nor will I engage with the medical anthropology literature.[36] This warrants a longer explanation. Before explaining why, I introduce the field and its main themes.

2.2 Medical Anthropology

Not characterized by one single theoretical paradigm, medical anthropology is described with different terminologies and subdivisions from one author or dictionary to another.[37]

'childhood' might be misleading, though as the discussed works' main themes are agency and 'being' (as opposed to 'becoming') I find them relevant for adolescents.

[34] Nor of women for that matter. I realize I may be in a privileged position, which I probably owe to those before me who stood on the barricades to have children and women included.

[35] In truth, my approach is probably similar to above discussed authors, what I do object to though is the special 'niche' they reserve for children, as I feel they are human beings like all others. I see anthropology as being about people, individuals, and I do not want to put people into essentializing categories (children, women). Not for the last time I refer to Rapport who suggests that the best way to deal with essentializing discourse is to ignore it: "an essentializing discourse in categorial thinking (along the lines of gender, class,...) is best refuted by ignoring it: writing as if it did not exist" (Rapport 2003: 16).

[36] I specify that I mean the 'standard' medical anthropology literature. As will become clear in the theory chapter, I do engage with authors writing on new medical technologies, but these could be classified under science and technology studies.

[37] See for example entries on 'medical anthropology' in the *Routledge Encyclopedia of Social and Cultural Anthropology*, 358-361 (H. Lambert); in the *Encyclopedia of Cultural Anthropology*, 1996, Henry Holt, 759-763 (A. McElroy); the *Dictionary of Anthropology*: Blackwell, 1997, 316-318 and the *Macmillan Dictionary of Anthropology* 1986, Macmillan Press, 187-188. For comprehensive overviews

Good (1994: 26) situates the origin of specific 'medical' anthropology (medical = studying biomedicine, as opposed to beliefs and magic) in the 1950s with anthropologists in the US becoming involved in international public health, to over the years grow more towards a comparative study of health care systems across cultures.[38] While these first studies brought 'culture' to play in the medical world, making it explicit that biomedicine is but one system among many, only in the 1960s appeared a more political and social critique of medicine and health, which has stayed prominent to this day.

Today the main theoretical debate in medical anthropology centres around two orientations: the objectivist-empiricist and the critical-interpretive, to use Lock and Scheper-Hughes' terminology (1996), while Good talks about rationalist-empiricist and relativist traditions (1994: 29-31). Lock and Scheper-Hughes locate this debate in the larger theoretical divide that has characterized the social sciences since the 1980s. While the objectivist perspective claiming to uncover facts in fact *produces* them —concretely in medical anthropology: biomedicine has been long exempt from cultural analysis— a critical-interpretive perspective seeks to understand social life as the negotiation of meanings —concretely in medical anthropology: the idea that all knowledge relating to the body, health and illness is (also) culturally negotiated and thus biomedicine needs to be analysed also as a cultural system. The question thus boils down to how or whether anthropological ways of seeing and knowing are epistemologically irreconcilable with biomedical ways of knowing and seeing. Two years earlier Good had mentioned the same epistemological key question.[39] He distinguishes four theoretical approaches in medical anthropology since the 1970's. The rationalist-empiricist tradition still persists, focusing on Health Belief Models.[40] Good

---

of different traditions in medical anthropology see Good 1994, 25-64 (Chapter 2: Illness representations in medical anthropology: a reading of the field) and Kleinman 1995, 193-255 (Chapter 9: The new wave of ethnographies in medical anthropology) and the edited volume by Sargent and Johnson (1996) that bundles essays by major authors in the discipline.

[38] Were Good to use the term 'anthropology of health and illness' he would see this field as having a legacy as old as anthropology. However, this focus would now be labelled 'ethnomedicine', which studies cultural systems of healing, but as mentioned before, terminology and traditions are shady.

[39] In Good's words: "[The question is] how to situate our analysis of cultural representations of illness in relation to the truth claims of biomedicine" (1994: 28).

[40] The HBM was developed by social psychologists in the 1950's, based on the idea that health behaviour depended mostly on beliefs about health goals and achievability of these: "the value placed by the individual on a particular goal and upon the individual's estimate of the likelihood of an action resulting in the goal" (Good 1994: 41). Note that goal setting and goal- oriented behaviour (and behaviour

objects that this strand privileges rationality as the main principle in health behaviour, he calls it a not value-free (for utilitarian) theory, employing a narrow concept of culture and human action while ignoring social factors, and macro-levels of inequality (1994: 41-44). On the 'critical-interpretive' side, Good specifies three other approaches, all focusing on the role of culture. While 'cognitive medical anthropology', focusing on categorization of diseases, can be criticised for approaching illness purely in mentalistic terms (1994: 51), the main conversation today is between two approaches that have developed in on-going dialogue with each other; the (Neo-Marxist) critical tradition, and the (meaning-centred) interpretive tradition. While the Neo-Marxist critical tradition sees illness representations as mystifications, misrepresentations influenced by larger political and economic forces that serve those in power (1994: 56-60), the interpretive tradition sees illness representations as culturally constituted realities, claiming that disease is not an entity but an explanatory model.[41] It recognizes interaction between biology and culture and gives a prominent place to embodied experience. Good calls for the development of a critical phenomenology, which could be a meeting ground for critical and interpretive anthropology.[42] Two years later Lock and Scheper-Hughes echoed this with their case for a critical-interpretive approach (1996).

If pushed to situate myself in the medical anthropology canon, I would find myself most at home in Lock and Scheper-Hughes' critical-interpretive approach—though Csordas' work has made me cautious about 'interpretive', as he claims experience does not get full weight— and Good's critical phenomenology. However, I have a problem with how medical anthropologists predominantly use the phenomenological approach. While aiming to overcome it, they start from a mind-body

---

cognitive therapies developed by health psychologists) are extremely fashionable and widespread in the adolescent diabetes clinics today.

[41] Arthur Kleinman who in the late 1970's defined the medical system as a cultural system, was the main propagator of the explanatory models of illness (EM). An EM is a set of beliefs which "contain any or all of five issues: aetiology; onset of symptoms; psychophysiology; course of sickness; and treatment" (Kleinman in Young 1982: 266). In 1982 Allan Young critiqued this approach for desocializing illness, and ignoring the fact that Western biomedicine is an ideological practice, whose power issues need to be criticised by medical anthropology (Young 1982: 276). In 1995 Kleinman himself writes he has become ambivalent about EM, saying he only intended to use it clinically, never as a complete ethnography (Kleinman 1995: 9).

[42] Good gives an example of how such a medical anthropology might look, with an account of the experience of chronic pain using the phenomenological analyses of sociologist Alfred Schutz. Starting from Schutz' six features of common sense reality (aspects that make the everyday world) Good investigates the 'unmaking of everyday life' in chronic illness (Good 1994: 116- 134).

dualism in which the mind (cognitive patterns) is continuously privileged: bodily experience is lived through interpretation and meaning negotiation (in the mind).

Though I have not found a solution to this eternal crux, I realized I would not find it in the medical anthropology literature. Hence I turned elsewhere. Closer to the source of phenomenology in anthropology. I needed a theoretical base, which medical anthropology could not give me, as it seemed to be standing on stilts. Like the anthropology of children, most of its theoretical effort appears to have gone into making a niche for its topic, convincing people that medicine was worthy of anthropological study and how it should be done (include culture, social forces, meaning, be critical). Now again this has become redundant. As before, I mind the separating, the dividing up of life in all its aspects, putting health in a special corner. As I did not want to feel stuck in one (even though fragmented) essentializing framework, and as the theoretical issues medical anthropologists dealt with were not the issues I wished to engage with, or at least not in the way they did, I moved on.

3. What This Work *Is*: Intersubjectivity II

3.1 Aim

"[No] need to master. To demonstrate, explain, grasp.... And then lock away in a strongbox. But rather to transmit: to make things loved by making them known."

Hélène Cixous (in Jackson 1995: 164)

I called this work an instance of intersubjectivity, pointing to the continuous dynamics between the field, myself, methodology and writing style. My approach towards the topic and my choice of anthropological 'tradition' was propelled by the field. From the start of fieldwork, two aspects of how diabetes was 'done' in the hospital struck me.[43] The first was the de-individuation of the young people.[44] Not actively pursued, but rather as a consequence of the hospital situation, young people were made into a group: 'young people with diabetes'. They might constitute this group on an afternoon in the

[43] Both aspects are thoroughly discussed in the ethnography.

[44] This de-individuation did not happen wittingly on an individual level, as most health carers were caring, concerned and personal with their young patients, having known them and their families for many years.

clinic, on the website with statistical details about paediatric diabetes in Millness, in articles by their health carers in *Diabetes Care*, but they are not a group, nor group members, to themselves. This virtual 'group' and de-individuation was enforced by a second aspect that struck me: health carers would take reality 'as is' —not as it could be— and as knowing this reality, thus saying "adolescents are like this", "adolescents do not like...", "adolescents want...". An essentializing discourse that did not leave much space for individuality, change and possibility.[45]

So this was it. I had to steer clear of any model to impose upon, or any system in which to fit, the data, as there were already so many interpretive frames at work in this diabetes context: clinical models, psychological models, health carers' experience. Neither anthropology of childhood nor medical anthropology could help me as they too came with baggage, a pair of focused binoculars. I wanted to avoid the instant 'add water and stir' approach of many (applied) medical anthropology articles: pick your illness and age group, do the interviews, choose your themes and add the most endearing, poignant, catchy quotes.[46]

I needed a different approach. To start from the bottom: observe what happens in clinics, listen to what people say and do and engage in a conversation with them, not only about what is but also about what could be. I needed to be able to "step straight out of doors" from my notebooks, "into life". A vivid illustration of 'reality' in constant flux and refraction, which thus can never be completely known, let alone taken for granted.

---

[45] Certain aspects of individuals would be commented upon in team meetings and thus come to constitute a caricature of that person: Kylie would be the one with the red hair, having dropped the paint pot, Simon the one with the baseball cap sutured to his head. Over-individuation leads to de-individuation, is that the mechanism of caricature? Out of the hospital in the diabetes world of international conferences and medical journals, this de-individuation was even more apparent. Top diabetologists giving presentations about anonymous patients, articles relating 'cases' bundling four years of a patients' life-with-diabetes in one paragraph, and of course statistics, trends, clinic results all holding an aspect of real people. At my first international conference, during a particularly scientific talk where I could not follow the biochemistry, merely observing the scene I saw science-fiction: a room with 1000 educated people listening to a speaker talking about "this 7-year-old girl" [*we are shown a slide with HbA1c levels over five months*], "this very clever 9-year-old boy lives with his dad" [*slide with a graph*]. I had been expecting a photograph.

[46] I admit this is a very unorthodox description of the design of computerized qualitative data analysis programs like Nudist, N-Vivo and Atlas.

The aim then of this dissertation is to question. [47] To question the essentializing discourse, and to show diversity and possibility —reality is not 'as is'. In medicine surely it could be taken 'as could be', as something to start from and to aim for, not as something to just accept and stay with.

How to do this? A minimalist anthropology, with no theory or analysis, merely showing people acting, interacting and reflecting?

3.2 Inspiration

"*Authenticity comes from a single faithfulness: that to the ambiguity of experience.*"

John Berger (in Jackson 1995:156)

Like the field coloured my approach towards it, a certain conception of reality grew with (and mutually constituted) my approach towards anthropology, fieldwork and writing. To situate myself in the theoretical canon, I would call my stance 'phenomenological', 'experiential', 'existential', 'intersubjective' and 'performative/praxis'. But what does this mean?[48]

Indebted to many authors, anthropologists and philosophers, who influenced my thinking, here I mention the three authors in whose writings I found most common ground and inspiration.

3.2.1 Michael Jackson[49]

As I identified most with Michael Jackson's way of seeing the world and anthropology, I describe how I read his conception of reality, knowledge and anthropological fieldwork.[50]

---

[47] Annemarie Mol recalls Foucault's mastery of "non-critical strategies for escaping dominant ways of thinking" (Mol 2002: 47). Instead of criticizing something, we raise questions about it, doubt it.

[48] Anthropologist Jean Briggs, when asked a question after a conference talk, asked that the question be rephrased as she "didn't do jargon". Together with the jargon the question dissolved.

[49] This reading of Jackson is based on Jackson 1995 (Epilogue in *At Home in the World*), 1996 (Introduction to *Things as They Are*), 1998 (Introduction to *Minima Ethnographica*), 2002a (*The Politics of Storytelling*), 2002b (*Familiar and Foreign Bodies*).

[50] While Jackson builds his views on philosophers and anthropologists before him, it would lead me too far to mention the history of his ideas here.

Jackson sees *reality* as relational: it exists intersubjectively: between subjects, which are people, objects and ideas, and which continuously make, unmake and remake each other (1998).[51] Thus there is no ontological essence, for example of object and subject, or body and mind, these are merely words we give to moments of experience (2002a: 263). If reality is relational, all the rest —(un- / re-) making that reality— is likewise socially, mutually constituted: selves, experience, and knowledge. This view celebrates ambiguity —Jackson mentions John Keats' 'negative capability': the capability of "being in uncertainties, [m]ysteries, doubts, without any irritable reaching after fact and reason" (Keats 1958 in Jackson 1998:14). Instead of one system with abstract theoretical knowledge having authority over the 'truth', there are life worlds, in which concrete lived experience, is (always contingent) knowledge.[52] The *self* (subject, identity, consciousness) is social from the start (it originates in social experience), and continually changing, which allows for our ambiguous and often conflicting experience of self (1996: 26-28). While still taking the self as an intentional agent, Jackson warns against conflating subjectivity, or consciousness, with any particular subject or self (1998: 6).[53] As reality is relational, and subjects are made and remade, Jackson is sceptical about abstract systems in which things fit.

Jackson then, practices an *anthropology* that focuses on the intersubjective, a "force field of human interaction" (1998:14), through an existential-phenomenological approach. He calls it an existential-phenomenological deconstruction of the abstract way of framing (anthropological) inquiry (1998:3). In other words, he deconstructs the abstract, by pushing to the fore the existential, the everyday life experience, through the phenomenological method.[54] I see it as him wanting to redress the balance, put the spotlight on the ignored body, experience and immediacy, to exist along reflection and

---

[51] With the 'intersubjective turn' Jackson denotes the relocation of subjectivity in anthropology (e.g. Goffman, Bakhtin, Sartre, Crapanzano): a focus on the interplay of subject and object, ego and alter. "Singular selves are simultaneously part of a commonality, sole but also several" (1998: 6). Philosopher-cum-anthropologist Katherine Young writes inspiringly about the intersubjective discourse to openly engage in fictive modes of enquiry to gain access to the Other. She explains how shifts in perspective and voice are legitimated by embodiment (Young 1997: Coda).

[52] I refer to Csordas' 'principle of indeterminacy' (1993: 152) that he sees as fundamental to existence. This fits in his program of embodiment as a methodology to approach cultures, as he phrases it 'somatic modes of attention'. "These indeterminate relations constitute the shifting existential ground" of cultural phenomena. Again, ambiguity.

[53] While I find this hard to grasp —how do they combine?— I do agree with his refusal to see subjectivity as entailing "a notion of the subject or of selfhood as some skin-encapsulated, seamless monad possessed of conceptual unity and continuity" (Jackson 1998: 6).

[54] Csordas talks about 'existential immediacy' (Csordas 1994: 10).

meaning. To inject some blood in the calcified theoretical veins. For Jackson does not do away with meaning, or reflection, rather he brings it down to earth, to life. It is back to 'things as they are', however not as they are to/in themselves but as they are experienced. He mentions Dewey's postulate of immediate experience: "things are what they are experienced to be" (Dewey 1905 in Jackson 1996: 10). This is the core of phenomenology: how things show themselves to us.[55] Jackson employs the phenomenological method of bracketing things themselves, (thus leaving out ontological or epistemological issues of reality) in order to look at our experience of them and arrive at existential immediacy, at our being-in-the-world (1998: 3).[56]

Anthropology is thus not about 'real' reasons and causes of things, rather its emphasis lies on the 'consequences', on what people do and experience (1996: 11). Jackson champions experience (always socially constructed and changing), by focusing on 'embodiment', with which he means our bodily subjectivity, our bodily being-in-the-world (all being is bodily being) and practical knowledge.[57] Jackson refers to Merleau-Ponty's notion of *praktognosia*: "my body understands its world, without having to make use of my 'symbolic' or 'objectifying' function." (Merleau-Ponty 1962 in Jackson 1996: 32). Phenomenology sees knowledge of the mind neither ontologically prior nor superior to knowledge of the body. Thus our gestures and actions do not necessarily depend on a priori cognitive understanding. Jackson states how in most human societies knowledge is a matter of practical competence and sensory grasp, and thus he critiques anthropologists who prioritize theoretical knowledge: they go and observe a complex activity and reduce it to the mechanism which lies beneath it (unknown to participants) and which we ourselves bring to the field (1996: 34). Instead, meaning should not be reduced to what can be thought and said, it may exist in the doing (1996: 32-33). Jackson mentions how in its original sense knowledge was a 'bodily ability to' (philologically related to 'generation' and 'knee') (1995: 169). Phenomenology recovers this sense by stressing the intentionality of consciousness.[58] Thus rather than (theoretical) worldviews Jackson favours (practical) life-worlds: embodied, immediate and experienced fields of intersubjectivity, social domains. *Knowledge*, and specifically

---

[55] 'Phenomenon', from the Greek verb φαινεσται: to show itself, to appear (Jackson 1996: 43).
[56] As Jackson says: being-in-the-world is between people "inter-existence is given precedence over individual essence. Relation is prior to relata" (1998: 3).
[57] "The meaning of practical knowledge lies in what is accomplished through it" (1996: 34). As I expand on Jackson's notion of embodiment in the literature chapter (Chapter 6), here I merely mention it.
[58] Merleau-Ponty: "Consciousness is in the first place not a matter of 'I think that' but of 'I can'" (*Phenomenology of Perception* 1962: 137).

anthropological knowledge, then is the knowledge with which people live, and is indeterminate and ambiguous.

As knowledge is a process of coming to know, rather than 'knowing', *fieldwork* is about the journey rather than reaching a destination. Jackson calls it "a method for putting oneself in the place of another" (1995: 163). It is standing within the field, experiencing, exchanging and sharing ideas, finding common ground (1996: 8). Participating in the conversation, rather than composing a final and one true account (1995: 165), implies a specific *ethnography*. Jackson admits this is a challenge. He suggests paratactic (putting next to each other without hierarchy) writing (1995: 164, 1998: 36). He uses narrative, life stories "the connective tissue of social life" (1998: 33) to write intersubjectivity (1995, 2002a) and also to counter "anthropology's tendency to flatten out difference and contingency in order to promote an illusory authority" (1998: 33). He suggests close descriptions of events and conversations to reveal meaning without defining it (1998:33, 36). All these are part of and constitute a minimal ethnography: "the minimalization of ethnographic fact is (...) an attempt to emphasi[ze] verisimilitude and contingency over system and structure" (1998: 36).

A limited synopsis to make explicit what inspires me in Jackson's writing: the space for *ambiguity* in knowledge, interaction and lived experience, and his concern with *authenticity*.[59] "[T]he authenticity of ethnographic knowledge depends on the ethnographer recounting in detail the events and encounters that are the grounds on which the very possibility of this knowledge rests" (1995: 163). I take authenticity not to mean 'true' (as one and only truth) but honest, faithful: as experienced, lived,

[59] Thus many aspects of Jackson's anthropology I have left untouched. I also did not make explicit where my approach diverges from his. To be concise: I find myself in Jackson's focus and method, but I do not find myself in what I believe (from his writings) is his motive for doing so. Not so much that I disagree, rather, this is not my issue. Thus while I am inspired by his intersubjective approach and focus on the life world, I do not care for the reasons why he does so. I explain. Jackson seems to take the 'intersubjective turn' to find an answer to a major anthropological question of how the particular is related to the universal, in other words, how the lived experience of individuals is connected to the virtual realities of history and culture. He then sees the field of intersubjectivity as a force field driven by a certain energy, by need, more precisely the need of human beings to have a sense of control, a drive to establish a balance between the world as is given and the world they choose, "the modus vivendi that is strived for in all human endeavour, i.e.: a balance between what is given and what is chosen such that a person comes to experience the world as a subject and not only as a contingent predicate" (1998: 3, 21). I find it reductionist to see one principle as driving intersubjectivity. Can it not just happen, with changing needs and modalities? I return to this in Chapter 8, discussing the relationship young people establish with their insulin pumps.

thought. Authentic, not shaped or coloured by abstraction, models, fashion or interest.[60] I find a similar propensity for authenticity and minimalism in the writings of Norwegian praxiology philosopher Jakob Meløe. Thus from phenomenology's (Husserl's) lifeworlds, through Jackson's eyes, to Wittgenstein's forms of life.

3.2.2 Jakob Meløe

Meløe starts from Wittgenstein's 'forms of life', stating how Wittgenstein replaced the concept of a building block, a basis, with the concept of an activity, a practice, a form of life, and replaced the concept of 'resting on' with the concept of 'being situated within'. (Meløe, *Remaking a form of life:* 4). Rejecting the standard view of cognition (the denotational idea of meaning), Meløe instead sees knowledge as arising in practices. The world is structured by the activity of agents, our activities in the world shape our concepts of the world which in turn shape our perception of it.[61] What we see is not a 'given', instead we see things that are relevant to our human practices. Meløe talks about 'agent perception' "those observations that guide the agent's operations" (1988) and the importance of seeing what there is to see. To see what there is to see, one needs to be experienced, a skilled observer, and one also needs to position an activity in the correct 'activity space'.[62]

3.2.3 Annemarie Mol

Philosopher-cum-anthropologist Annemarie Mol also focuses on practices but sees them as constitutive not only of our knowledge, but also of reality. While Jackson and Meløe 'bracketed' reality (its ontology) to instead focus on our experience (Jackson) and knowledge (Meløe) of it, Mol questions reality (its very ontology) and states that in fact

---

[60] A third aspect intertwined with this ambiguity and authenticity is *modesty*, linked to his minimalism, a refusing to take authority by claiming truth and closure. For example, in the epilogue of *At home in the world* Jackson states that he relates the events of his fieldwork in Australia as narratives, so as to avoid "the radical construction and systematization that mark academic writing" (1995: 156).

[61] "As practices are brought into being, altered, left to disappear, so the concepts and perceptions proper to these practices are brought into being, altered and left to disappear, as *live* concepts or perceptions" (Meløe n.d. *Remaking a form of life*: 3).

[62] He gives the example of interpreting a game of chess through a navigator's eye (and thus not seeing) or seeing a rock to climb through a climber's eye, looking for footholds and a route (and thus seeing) (Meløe 1988). He talks about the fit between seeing and doing (Meløe, n.d. *Two Landscapes*: 390), how we get to know something by doing it, by working on it, for example getting to know the material by carving it. He concludes that "not seeing and not knowing that we are not seeing (what there is to see) is a kind of non-existence" (Meløe 1988). For example, if I am blind to chess, chess does not exist in my world and I do not exist in the world where chess exists. I can only agree with Meløe that this is a terrible thought.

reality is multiple. In short, she suggests that multiple practices lead to multiple realities.[63]

"Ontology is not given in the order of things, but ontologies are brought into being in common practices" (Mol 2002: 6). She calls her ethnography 'praxiography': describing practices, describing how things —in her case the illness of artherosclerosis— are being 'done', how reality is enacted (2002: 31-32).[64] Taking reality as multiple, Mol's focus then is not on coherence as in one whole, but on *connectedness*. It is about seeing unity in an ambiguous way.

These three authors coloured my focus in this dissertation: lived experience, intersubjectivity, no 'given', but making and unmaking in relationships and practices.[65] This dissertation is an exercise, its tone not argumentative but reflective and illustrative.

3.3 In Practice: A Focus on Intersubjectivity: Existential Dynamics

" We won't find ourselves in some retreat, but on the road, in the town, in the midst of the crowd, a thing amongst things, a man among men."

J-P Sartre (1939 *Being and Nothingness*)

If reality is relational (Jackson) and constituted by our practices (Mol), or at least our knowledge of reality constituted by them (Meløe), then this dissertation needs to acknowledge and practice this relationality and mutual constitutiveness.

This focus on lived experience and practices may appear puzzling, as the type of fieldwork I conducted does not seem to lend itself to this existential approach. I did not get to see (let alone participate in) much action, or everyday existence, as most fieldwork consisted of 'interviews', 'listening in' and talking to people. But this is how I

[63] Since I discuss her ideas more elaborately in the literature chapter (Chapter 6), here I merely touch upon them.

[64] Rejecting the bracketing of practicalities in many anthropological studies of disease (2002: 36), she makes a case in point to focus on them. This is the approach I have been looking for.

[65] Of course so many other authors have shaped my ideas and approach in anthropology, though this would be another introduction. I mention as main influences Rapport's fervent crusade for the individual and his/her worldviews, philosophers Charles Taylor's 'humans are sense-making animals', MacIntyre's narratives, Anette Baiers' and Sheila Benhabib's 'philosophy of care'. All combine in a focus on individual agency and sense-making, with any individual identity as relational.

felt it had to be written. This approach allowed me to keep the people central, what they said and did, with doubts and contradictions, life as it is. The alternative to the theoretical and ordered world of biomedicine and its research. In what concerns methodology, existential dynamics meant chats and thinking together. Specifically for the topic of the insulin pump (see Part Two), I felt I missed out on so many 'automatisms' of life with it, that I decided to wear one myself. Thus embodiment as method: how does it *feel*? What do you *do*? Embodied knowledge.[66]

I look at the existential dynamics of 'living with' and 'doing' diabetes (focusing on interactions between the young people and the health carers), and of 'living with' and 'doing' insulin pumps (focusing on the young people and their relationship with their pumps). While I started the research investigating how young people lived with diabetes and their pump (cf. Jackson), I ended up thinking about how the pump, the young people, health carers, parents, clinic consultations, cultural ideas, and social circumstances interacted and performed different diabetes (plural) (cf. Meløe and Mol).

Other dynamics are at play in this text: the existential dynamics of (my writing of) this text. 'I' am very present. This is deliberate. I could leave out the 'I', the text would seem more neutral but would be less so. While this approach (consciously putting myself in the field, being part of the conversation) can easily be critiqued for being narcissistic and solipsistic, I suggest that the advantages outweigh the disadvantages.[67] As I feel it is the only way I can write authentically. It is to make explicit the limitations of this text: all I can say is what I have seen, experienced, done, read and heard and how this serendipitous flow made it into a text.[68] Also to give transparency to the coherence of this text: me-the-fieldworker, me-the-girl-from-Belgium, me-the-anthropologist: performances that conflict, intertwine and are held together. It is to show how things relate and to make explicit that when things happen (like this dissertation) there is a lot of effort involved to make it work (see Chapter 6 and Law and Singleton

[66] Meløe writes how the skilled observer of a fisherman at work is another fisherman. We do not master the various concepts of a fisherman's skills, unless we recognize them when we see them; and we learn to recognize those skills by practicing the same art ourselves (Meløe 1988). Concretely for this research, apart from the skills of operating an insulin pump (which I never mastered as I did not need it in all situations), until I get diabetes I will not know what it means to have diabetes. But then for every person at every moment it means different and several things.

[67] Also, it might be more narcissistic to adopt some academic abstraction and thus equating one's own interpretation and selection with the theoretical 'truth'.

2000). And —though it did feel so at times— not just from me. But from the anthropology books, the lecturers, the authors, the young people, the health carers, the clinic, the pump, my body, the diabetes research articles, the TV programmes, the newspaper articles, the food, and the jokes —ad infinitum— involved.

Personal involvement in this text is thus not only a theoretical but also a moral necessity. Throughout this work my voice will come through.[69] Here I merely wish to support my practice of 'ethnographic judgement' with Hannah Arendt's words (in Jackson 2002a), as she phrased so eloquently what I had been struggling with.[70] We can only be 'objective' if we put our lived experiences and consequences of the phenomena central, as these make up what things are, and mean. Arendt: "If I describe these conditions [*she mentions how describing Nazi concentration camps as 'hell on earth' is more 'objective' than leaving out these feelings*] without permitting my indignation to interfere, I have lifted this particular phenomenon out of its context in human society and have thereby robbed it of part of its nature" (Arendt 1953: 78). While there is no comparison, I chose to mention my indignation and worry at what I experience in this research, as people's lives are concerned.

This dissertation then is a minimalist ethnography: a sketch of life, of people acting, interacting, thinking, judging, making sense; and in all this, 'doing' reality. It is an observation and a detailed description of interactions, conversations and life stories, with some reflection. It is a trying to see what there is to see. It is about how diabetes is 'done', enacted.

Its relevance? Not much, but perhaps not less than a theoretical and analytical account. I hope it is a *document humain*, which, since we write about people, is all we can hope for. So my aim then is, to borrow Hélène Cixous' words: "To make things loved by making them known" (Jackson 1995: 164).

---

[68] As Crapanzano phrases it: "Through the seemingly transgressive montage, I want to stress not only the arbitrariness of our constructions but the process of construction itself..." (Crapanzano 2004: 10).

[69] Though everywhere, most specifically in the context Chapter and discussion Chapters 5 and 10.

[70] As mentioned by Jackson when he exposes how the false dichotomy between objective and subjective positions is overcome by intersubjectivity, something Arendt was well aware of (Jackson 2002a: 263). Arendt uses the example of Nazism "To describe the concentration camps *sine ira* is not to be 'objective' but to condone them (...) I think that a description of the camps as hell on earth is more 'objective', that is, more adequate to their essence than statements of a purely sociological or psychological nature" (Arendt, 1953. "A reply" *Review of Politics* 15:76-84: 79 in Jackson 2002a: 263-264).

But how to write transparantly? [71] Transparency in the way that this is a constructed piece. It has gaps and questions and spaces in between. A "theory-analysis-plus- quote" text would be too polished, sterile, trying to give things a place, to make it neat and a whole. Instead there is difference, interference, clashing, but still, through all that, indeed, things hold together. Mutual inclusion. Chaos, but coordination, multiplicity but not pluralism. I borrow heavily from Mol, as she captured so clearly this chaos in my head, that caused irritation and frustration because things did not fit. Luckily, I know now. For if things and people had not kept moving and pushing, it might have meant I had tried too hard and succeeded in taming the sharp edges, the movement, the incongruities, the overlapping and the gaps: But they exist, in the world. And I hope they are in here.

*

This ethnography takes the form of a **collage**, all elements making up a refracted picture.[72] As such, there are many different ways this work could have been written, many ways it can be read. Because of the written format I had to make a choice. Perhaps the way I prefer it to be read is as a concrete case of how a (uniform) technological device, in this case the insulin pump, is embedded and used in a specific social and cultural context.[73] In Part One I sketch the social and cultural context of diabetes care, in which, in Part Two, the insulin pump enters as a new type of therapy.

---

[71] Concretely, for example, how to 'write up' 20 one-hour interviews with engaging young people? I have not found a solution. I feel I have 'given in', succumbed to the rationale of producing a text, by following my own narrative interlaced with details and experiences. I feel uncomfortable. As if I leave the people, with their lives and doubts and thoughts I so wanted to be central in this work, at the door.

[72] While writing this I read Crapanzano and find he writes similar things so eloquently. He calls it a 'montage'. "I've come to prefer the puzzlement generated by the montage to the complacency offered by the easy explanation" (Crapanzano 2004: 6), thus choosing to stress "discontinuity and disjunction" (2004: 9).

[73] See Strathern's foreword in *Consuming technologies* (1992: vii), an edited volume bundling rich empirical studies showing this point. In the same volume, Hirsch and Silverstone urge us to see everyday technologies as social and symbolic as well as material objects (Silverstone & Hirsch 1992: 2).

The plan of this dissertation is as follows:

The introduction relates the practicalities of fieldwork and situates my approach in the broader anthropological context.

The context chapter, next, sketches the wider background to the people and their actions: the state, approach to health, ideas on diabetes.

Part One, 'Doing Diabetes', opens with a vignette on Charlie, a 'prototype' Millness adolescent with diabetes, to then ethnographically dive into the diabetes setting at Millness Hospital, portraying the health carers (Chapter 1) and the young people (Chapter 2) and to follow the same format with Dr. Dumoulin's diabetes centre in Brussels, Belgium: the health carers (Chapter 3) and the young people (Chapter 4). This first part concludes with an analytical chapter (Chapter 5) comparing the approach to diabetes care in the two portrayed centres.

Part Two, 'Doing Diabetes With an Insulin Pump', introduces a new actor/actant in the sketched diabetes scene, the insulin pump. Opening again with two vignettes on young people with pumps, Callum and William, I then extensively discuss the literature that informed and shaped my approach to the topic of embodiment and technology (Chapter 6). After this theoretical framework, two ethnographic chapters portray the Millness pump therapy for the health carers (Chapter 7) and the young people (Chapter 8). A comparative chapter (Chapter 9) discusses pump therapy in diabetes centres in Boston and Gothenburg. This second part finishes again with an analytical chapter, in which I compare the Millness approach to the other centres, and look for some clues that might explain the differences, both in approach and medical outcome.

In some Closing Remarks I wrap up all previous chapters into some collage/ montage; the people, conversations, and actions described put in a kaleidoscope, giving it a few twists to make a new image, only to be moved again.

In Appendix 1 I give an ethnographic account of an eight-day adolescent diabetes camp 'Pinewood Camp' in the Scottish Highlands, the only time I had the privilege to dwell in 'diabetes-land': 24/7 time spent with young people with diabetes.

Appendix 2 gives the medical story on Type 1 diabetes and how it works in the body.

Finally a Glossary explains some medical diabetes terms that feature throughout this text.

And all the above —and what follows— in three words?
People doing diabetes.
Or with Macintyre's words: "The stories that are lived before they are told" (1984: 212).[74]

***

[74] Though Jackson questions this view, stressing instead the *telling* of stories, as that is where he finds the existential agency, in the 'narrative imperative' (2002a: 15).

Context

Living in Millness, Scotland, with Diabetes

A context chapter in an anthropology thesis: an anomaly? Anthropology is about context, the ethnography that follows brims with it, so what is this about? Here I sketch the framework in which the practices and conversations that follow are situated, the framework that shapes both the observed practices and my understanding of them. This chapter is about discourse. Powerful discourses on Scotland and Millness, the 'nanny' state, health, adolescence and diabetes, I had to become aware of and that in turn helped me to understand.[1] As people 'speak' in the ethnography, here I voice the discourses present in the media (newspaper, radio, television) and in social science studies. The 'context' then is the context as it is printed, as it lives in people's heads and forms the basis for their actions and interpretations; and as it starts to live in my head, informing my attempts at making sense.[2]

Having lived in Scotland near the city of Millness for a year, my first plunge in the field, the diabetes clinic at Millness Hospital, made me look at the familiar place through newly focused spectacles. *[My thoughts in italics.]*

---

[1] While this chapter is structured around place, the state, health and adolescence, all are intertwined. It could thus just as well have centred on state involvement, non-accountability, individual freedom and choice, all key themes in what follows.

[2] I concur with Schlecker and Hirsch (2001) pointing out the 'crisis of context' in social sciences: how the quest for ever more angles of context still does not lead us to the essence of things. The authors explain this is because there is no essence of things to be found and that this is exactly what causes the problem, namely the fact that we suppose there is one and that in looking for it we presuppose how a priori all things are unrelated, stand alone. (They mention Strathern's 'merography': making "sense of things by describing them as part of something else" 2001: 71). This is not how I use context here, as some surrounding backdrop to bring to the fore the true essence of things. But rather, as will become apparent throughout this work (mainly in Chapter 6), I hold a more interrelated and dynamic view of things: things come into being (and are continuously a 'becoming') by the relationships they are in.

Millness Paediatric clinic, consultation room

Millness Paediatric clinic, consultation room

Millness City Centre

Millness City Centre (2)

I am sitting in at the Young Adult diabetes clinic, in a grey consultation room with silver haired Dr. John. Expecting a formal conversation between doctor and patient about illness management, questions by the patient and advice by the doctor in response, instead I witness a casual chat between a bubbly 17-year-old girl and impressive senior physician John.

Dr. John: "What do you have for lunch?"

Girl: "The usual: packet of crisps, a diet coke, a sandwich and a Mars bar."

[A Mars bar? Sugar? She is diabetic, does that not mean she can not have sugar at all, is that not why there is 'diabetic chocolate'?]

Dr. John: "What kind of crisps?"

Girl: "Walkers."

Dr. John: "Oh yes, good choice, Walkers are my favourites. Everything OK for the rest, insulin? You take your injections?"

Girl: "Yes, apart from when I forget."

Dr. John: "Try to remember."

They agree the girl will come back to the clinic in three months time.

[Baffled. Intrigued. Am I in the right place? No dry conversations but quite entertaining chats? Dr. John is so understanding, he does not tell the patients off. Why does he not tell them what to do, or check whether they know what to do?]

That afternoon Dr. John sees seven patients, some briefly, when they are fine and/or taciturn, others longer, when they enjoy chatting about school, sports, holidays.

Only with one girl, skinny and pale, the consultation has a different tone from the start. When John asks her "Are you still on your drugs? Which ones?" I expect to hear the usual insulin doses, "20 of the orange, 50 of the blue in the evening", when she starts summing up "Tomazepam, Diazepam..." and other 'zepams'.

[I had forgotten, I am in Millness, drugs are a reality, also in a diabetes clinic.]

The room has gone silent. I look up from my notebook, the girl is looking down, her face red, John is looking at her, only then I see the girl is crying. In the ensuing halting conversation I hear Kylie (21) lives on her own though she has been staying with friends who get her drugs, she has pawned her new stereo for drugs, her father does not want to know her now he has another girlfriend. Kylie does not take her insulin very often. None of this is new to John, he has known Kylie for some years. When he asks her what they can do to try and help her, Kylie does not respond.

John continues "I just worry we never seem to make any progress, the thing I'd like to see is that at one stage you would take care of yourself. You never really do that do you? Do you think you're gonna get through this?"

Kylie has her voice back: "Some days I do, some I don't."

Dr. John: "I think you'll do OK. But once in a while you should stop and think: somebody would need to look after Kylie, 'cause nobody looks after her at present."

They agree Kylie will come back to see Dr. John in two months and she goes. John turns to me, sighs, and sees my alarmed look. I do not contain myself anymore: "She comes back only in two months? She is on drugs, does not take her insulin, is on her own? Who takes care of her?" John agrees but says there is nothing they can do, diabetes nurse Jane is in touch with Kylie and visits her at home. That makes me feel a bit better, someone checking up on her. John concludes: "The important thing is that she is open about not taking her insulin. And that she keeps coming to the clinic." Nurse Jane comes in and sighs: she is not getting anywhere with Kylie.

Having naively presupposed a blank mind on diabetes, this first contact confronts me with my own preconceptions. Not only do I realize I am used to a different diabetes, a different contact with doctors, different ideas about relations between parents and young people, I am also forcefully thrown into Scotland, more precisely Millness. Millness, though now being promoted as the 'sunshine city', still more famous for drugs, drinking, violence, third generation unemployment, highest rate of teenage pregnancies in Europe, and like other places in the country, an unhealthy diet. My initial puzzlement, attempts at understanding and worries will stay with me throughout fieldwork, shaping my approach to the topic, and will consequently be the theme running through this dissertation.

One of the points I suggest in this thesis is that the treatment of diabetes in young people is based on a discourse on adolescence that in turn is nested in a discourse on Scotland. Concretely, though in 2004 a standard work on social and economic change in Scotland since 1980 demonstrates with ample quantitative data how Scotland is now a "more affluent, comfortable and pleasant place to live in than two decades

ago", it seems that the Scotland (and Millness) in people's minds is still more characterised by the epithet "deprivation".[3]

An excerpt from my fieldnotes:

As I ask for a ticket to Millness Hospital, the bus driver jokes that I don't look ill. I understand him better as at every stop the bus fills up: an obese man, smelling of alcohol, talking to himself, an old lady bent over from arthritis, destitute old people and young girls with pregnant bellies or prams. The windows steam up, a smell of urine and sweat lingers. I read the notices on the ceiling. An ad for nursing studies "more rewarding than a Lottery win", an invitation to "Call Parentline: the helpline for parents", an ad by the East Millness Women group against "Domestic Abuse", a poster for HIV prevention and safer sex "information on drugs, injections, free condoms and pregnancy testing". This last ad is by the Harm Reduction Team, a name well suited for the entire social services in this country, I think. Harm reduction instead of harm prevention. Not used to seeing all these social, personal problems advertised in a bus, I recall similar ubiquitous stickers in (women's) public toilets "Pregnant?" offering telephone helpline numbers. Having heard rough stories about Millness I see the ads as a confirmation. Or am I wrong? Are these ads actually a positive sign? Here people tackle problems, they are out in the open and help is offered. I remain unconvinced. I muse that social services and voluntary organizations are the new family in Millness, a very extended family supporting the predominant single mum with child.

Millness Hospital, a large state-funded teaching hospital, is the main hospital for a large catchment area.[4] Consequently, the approach by the diabetes team is based on life in Millness.[5] Discussing the economic, cultural and social rise that Scotland has experienced since 1980, Paterson et al. (2004) are careful to point out a remaining

---

[3] Paterson, Bechhofer and McCrone 2004. For a comprehensive overview of culture and society in Scotland in the 20th Century see Dickson and Treble (1992) *People and society in Scotland. 1914-1990* and for recent but major changes in the last two decades see Paterson, Bechhofer and McCrone (2004): *Living in Scotland. Social and economic change since 1980.*

[4] Millness Hospital, the first new teaching hospital to be built in Britain after the second world war, is linked to the medical school of Millness University.

[5] Millness, Scotland's fourth city with a population of 144.180 inhabitants (66.980 households), does not compare favourably with the rest of Scotland (based on the 2001 Census data). Almost half of Millness' residents live in rented accommodation, council flats in mainly high-rise tenements. Compared to the larger cities of Edinburgh, Glasgow, Aberdeen and Scotland as a whole, Millness has more semi-skilled and unskilled manual workers, a lower average gross weekly wage (£ 411) and the highest rate of teenage pregnancies (*About Millness 2003*).

minority who do not have access to more goods and better standards of living. I think Millness houses a fair share of these less privileged people.

1. The Nanny State

In Scotland I am struck by the strong presence of the state: not only in the form of benefits but also in education, leisure, health and diet. Though enjoying similar benefits and a state-funded health system and schooling in my home country (Belgium), the Belgian state is more or less 'absent' from my daily life, whereas in Scotland I seem to run into the council at every corner. As this active state seems to be of key importance in order to understand certain aspects of Scottish life, in particular regarding people's health beliefs and actions, I point out three related aspects of it.

The famous term 'nanny state' points to the intimate relationship Scottish people have with the state, specifically their *reliance on the state as a provider of resources* such as council housing, child and unemployment benefits (Knox 1999: 252).[6] High levels of unemployment and cycles of poverty have led to widespread deprivation,

[6] The term 'reliance' is significant. It has a connotation of trust and personal choice and initiative, in contrast to 'dependence' that happens by necessity. In his 1989 article "Scotland is different, OK?", Dickson rejects English Conservative Nigel Lawson's mention of the Scottish 'culture of dependence' on the state. Dickson: " If he had talked instead of 'reliance' he might have been more accurate. Particularly in housing and health and in crucial areas of everyday life, many Scots do rely on government expenditure. (...) Historically, Scots have also experienced poor quality housing and social conditions, and these are reflected in mortality rates for such diseases as heart disease, bronchitis and lung cancer far above the European norm. These factors are, in turn, translated into a special reliance on government spending" (Dickson 1989: 60). To me, Dickson's quote is illustrative of a certain propensity I encounter in many Scottish people, to take pride in having suffered hardship. I wonder whether this is part of the reaction against the 'Scottish cringe', the denigration of Scottish culture, the pressure to shame Scots (mainly writers, artists, scientists) out of their Scottishness (Scott 1993: 11). Though this is not the place to go into this, let me illustrate this 'reliance' point further by quoting (the present) Chancellor Gordon Brown. In his 1987 introduction to an edited volume on poverty and deprivation in Scotland (Brown and Cook 1987) Brown takes a strong stand against Thatcher's Conservatives who had just won the election after a long Labour rule. In opposition to Thatcher's policies of reducing public spending on health and social security, Brown argues for a larger welfare state. Contrary to what Conservatists claim, Brown states that Scotland's poor are "not poor because they are Scottish (...) in other words, Scotland's high levels of poverty are not the result of feckleness, incompetence, poor household budgeting, excessive drinking or smoking or personal deficiencies amongst 'the poor', they are poor because, if they are not unemployed, they are in the wrong job, generation, sex or class and because the welfare state fails to compensate them for it" (Brown 1987: 12). In short, Brown states that the problem is unemployment, not the unemployed, and that the safety net provided by the welfare state is insufficient.

leading a large number of people to depend on the state for survival.[7] Next to relying on the state, people also experience widespread *state intervention* and thus social control, in several areas of public and personal life. With the decline of the influence of religion and voluntary organizations after 1945, the state has taken over their 'policing' role in the social lives of the working class, for example in providing leisure facilities, in the form of providing sports fields, outlawing rough street culture, and legalizing gambling. The state is also involved in education, which according to Knox has played a significant part in homogenising culture and social attitudes (Knox 1999: 270). This relying on the state and enduring social control by the state hinges on a third aspect, for which I borrow Paterson's term, a strong *belief in public action*. Though the welfare state which offered 'cradle to the grave' coverage has undergone changes towards privatization and individualism, in 2004 people in Scotland still have a strong attachment to community and "egalitarian collectivism" (Paterson 2004:155).

I focus on this strong state presence with the aim of understanding an attitude of non-accountability that struck me in Millness, an absence of personal responsibility, which I discuss below in relation to personal health.

2. Doing Health

> *"I believe we have higher levels of vulnerability. The question is what makes us more vulnerable. One answer is deprivation, which is driving a great deal of it. However, I think there is also a 'Scottish effect' that makes us more unhealthy. It could be something cultural such as a sense of fatalism or something behavioural such as eating less fruit and vegetables."*
>
> Professor Phil Hanlon, adviser to the Scottish Executive on public health
> *The Sunday Times* (14-12-03) [8]

[7] See Knox 1999, chapter 25 and especially p 260-264 for a clear interpretation of Scottish working class culture. Knox makes the comparison with England, making explicit the higher degree of deprivation, unemployment and thus higher dependency on the state in Scotland.

[8] The title of the article is "Scots face growing risk of early death", the picture of a man tucking into a hamburger has the caption: "Over the top: poor diet, smoking and lack of exercise may encourage Scotland's high death rates, but the 'Scottish effect' may be the real answer". The term 'Scottish effect' was coined in the late '80's to explain the extra difference (with England) in bad health after all known factors had been accounted for. (See for example McCrone 2004: 22-24, who urges us to use the term with caution).

Though medicine has a centuries-long prominent tradition in Scottish cultural life, the nation does not enjoy good health.[9] Scotland's health has improved in the last 50 years, but it has done so at a slower rate than most Western European countries.[10] The state, in tandem with health professionals, has been increasingly involved in improving the nation's health. The initial (19th Century) focus on improving environmental conditions and controlling infectious diseases, grew into provision of welfare services and culminated in making medicine accessible to all, with the establishment of the National Health Service (NHS) in 1948: "from the cradle to the grave" we'll take care of you.[11] However, most social commentators mention a shift in the government's health policy since the 1980s. Confronted with a too big demand on health services, mainly by rising treatment costs of (lifestyle-related) illnesses like cancer, heart disease, obesity and diabetes, policymakers put the stress back on the personal responsibility for health. In addition to financial pressures and vested interests, the government had also grown weary of intervention because of the importance of personal freedom. Thus from the 1980s the government policy focused on health education, mainly in the form of press reports, encouraging the individual to take responsibility for her own health.[12] One major topic for health education is to change the 'national diet' by Healthy Eating campaigns, appropriate as a social report published by the Scottish Executive in 2001 states that diet "is the second most important factor in preventable ill health in Scotland behind only smoking".[13] Optimistically the Scottish government website bundles several projects under the banner "Improving Health in Scotland – THE CHALLENGE" with a vision for Scotland in 2020: "A thriving Scotland with appropriate working, housing and living conditions, *less smoking*, *healthier eating*, more activity in daily life and *less binge drinking*, (...) fewer early deaths from heart

[9] On the rich Scottish heritage in medicine see for example Nicolson (1993).
[10] In 2004, McCrone labels the Scottish population "notorious for ill-health by international standards" (McCrone 2004: 20) and there are still significant inequalities of health, determined by deprivation in the form of unemployment, poverty and social housing, as mentioned before (Knox 1999: 263 and Nicolson 1993).
[11] See Hardy (2001) for a concise history of health and medicine in Britain.
[12] I followed the Scottish press leisurely over a period of four years, 2001-2004. Every weekend Scottish newspapers would run an extensive article on 'health issues' in Scotland: binge drinking, cancer, diabetes, bad diet, earlier deaths, obesity etc. Scotland would always be unfavourably compared to England and the rest of Western Europe.
[13] *Scottish Social Statistics* 2001, Edinburgh: Scottish Executive, quoted in Bechhofer 2004: 135. Another example is the 'Healthy Living' campaign that has been running in Millness for a few years. Geared towards the most deprived areas of the city, it focuses not only on diet but also exercise and lifestyle.

disease, diabetes and cancer. Individuals and organizations taking more individual and corporate responsibility".[14]

I say 'optimistically', as similar initiatives have tended to fail due to strong consumer preferences (Hardy 2001: 152). "It is a matter of frequent comment that the choices made by the people of Scotland are not always in the best interest of their health" (Bechhofer 2004: 133). Consumer preference, choice: a key concept in this theme of health. In 2004 Bechhofer states that though the choices might not be 'good', at least, following the rise in living standards, people are able to make choices. This relates back to the *Black Report* (1980) that demonstrated significant class-related inequalities in health, which could only be explained as the result of poverty and material deprivation. The government rejected this explanation, arguing instead that the inequalities were merely a matter of life-style, and thus down to individual behaviour and responsibility. Education would teach people how to fit the healthy living model, there was no need for the government to intervene structurally.[15] Seven years later, in the *Health Divide* (1987) biologist Whitehead confirms the findings of the *Black Report*, by quoting new studies showing that material factors *do* affect health and health-related behaviour, it not being merely a matter of choice.[16] In 2004 McCrone writes that though living standards have improved greatly, there are still pockets of deprivation. I think Millness harbours some of those pockets. To what extent then is the unhealthy diet of people in Millness, and more specifically the young people in the present work, a matter of choice?

> *Spiderwoman hangs from the kitchen ceiling; below, a family is gathered around the table ready to tuck in to chips and chicken nuggets. Spiderwoman, holding a bowl of fruit, cannot contain herself any longer: 'That's it, I'm going in'. Nice woman tries to stop her: "Wait, there's another way to make them eat healthy*

[14] Scottish government website: www.scotland.gov.uk/library5/health/ihis-02.asp, (my emphasis).
[15] Hardy 2001: 171.
[16] Whitehead deflates the 'culture of poverty' idea that explains poor people's bad health by claiming they have more negative concepts of health and lack an orientation towards the future, which inhibits preventive health action. An example of material conditions affecting health and health behaviour is low income that affects the choice of diet. Food is regarded as a flexible item and often a first area to save in, in order to pay the rent. Cheaper food is high in sugar and fat. She quotes a study on how mothers cope with caring for the family on a low income: "Actions which would be labelled 'irresponsible' by some professionals, may be the only way in which mothers can stay sane and act responsibly". For example they feed their kids sweets to keep them quiet (Graham 1984 in Whitehead 1988: 302).

food...." Spiderwoman "too late" has already launched and is swaying with her fruit bowl above the table, the family is terrified. Nice woman enters the kitchen and puts a plate with ham sandwiches on the table, smiling to the family: "Don't worry, she'll self destruct in 30 seconds" Indeed Spiderwoman plus fruit bowl are snapped back up to the roof by the elastic thread. The family happily tucks into the ham sandwiches.

TV ad for Kingsmill bread

I have difficulty understanding the Scottish 'national' diet.[17] Why do people not eat fruit and vegetables? Or to put it the other way: why do they eat such fat, sugary and non-nutritious things? Is it the cost?[18] Or rather taste?[19] Climate?[20] Choice? Lifestyle? Habit? [21] The Scottish effect?[22] Whether it is not being able to, not knowing, or even a choice for unhealthy foods, many people seem not interested in eating healthily, nor in being healthy. Or rather, they are not responsible. So often have I heard that it is not up to them to be healthy; it is the doctor's job to take care of them. Similarly when talking

[17] I find it even harder to understand that young people with diabetes, who would benefit greatly from refraining from fat and sweet foods, do not. Nor are they encouraged to do so by their diabetes health carers.

[18] People in Scotland spend less than one fifth of their income on food (Bechhofer 2004: 135), while fresh fruit and vegetables are expensive, unlike sweets, biscuits and tinned foods.

[19] When asked, people often tell me they eat these things because they taste good, taste being the most important aspect of food.

[20] Often mentioned together with the taste: it is so cold and grey outside, people need comfort food: chocolate, chips. Unlike when they are on holiday abroad where the sun shines.

[21] For some time I mistakenly put the unhealthy diet down to the spread of convenience foods and saw it as a quite recent phenomenon, wondering when it all went wrong. When did people stop eating fruit and vegetables? I found out they did not stop, they just never did. The national diet is indeed cultural heritage. In a study on the Scottish diet, comparing data of industrial cities (Edinburgh, Glasgow and Millness) at the end of the 19th Century, Campbell found that in Millness, while the income rose, nutritional standards went down. Though earlier investigators brought this down to laziness "When it came to the question of using the ready cooked bread or the uncooked oatmeal, laziness decides which, and the family suffers" (Paton, Dunlop and Inglis 1902: 79 in Mintz 1985:128). Campbell puts this into the context of the jute industry in Millness, which thrived on female labour. "When mother is at work, there is no time to prepare porridge or broth, breakfast and dinner become bread and butter meals." As vegetable broth was the only form in which Scottish people ate vegetables, it meant they ate no vegetables at all. Families lived on white bread and tea, a cup of tea made a cold meal into a hot —I wonder, is this where the term 'tea' meaning 'dinner' in Scotland comes from? "Ye'll have had yer tea?"— and after 1870 jam became virtually the only way the working class consumed fruit. This was indeed the birth of 'convenience food': jam which did not spoil (unlike butter which had to be kept in the fridge and was more expensive), purchased white bread instead of porridge which had to be prepared, tea instead of milk (to be kept in fridge) and home-brew beer (Campbell (1966) in Mintz 1985:128- 129). Convenience food is thus not a recent phenomenon. Eating fruit and vegetables is not a lost habit; it was never part of the diet. Thus the Healthy Eating campaigns of eating '5 a day' are not re-education, reminding people of what once was, rather it is education.

[22] Indeed a tempting one and for all explanation. It would easily make this dissertation redundant.

about housing and unemployment benefits, the state needs to help them. And the state does help, the community cares. Is it then surprising that when the state starts to stress individual responsibility for health, people find it hard to take that on board?[23]

3. Being Adolescent

More than 40 years ago, in 1962, Phillippe Ariès called the 20th century the 'century of adolescence'; adolescence is the favourite age, we want to linger in it as long as possible. While it is hard to marry this with the discourse on adolescence that follows, it still is the case that "the adolescent was to become one of the most prominent types of our time, dictating its values, its appetites and its customs" (Ariès 1962: 30). Thus while reading the (rather grim) discourse that follows, it is important to keep in mind that at the same time 'youth', that stage in life and the people representing it, is envied by many adults, in order to understand the accommodating approach of (professional) adults towards adolescents.

[23] I am puzzled how to combine the government's 'respect' for individual autonomy with health education. On a personal note, it seems ironic that in this country so wary of patronizing attitudes, I feel patronized as never before. Not used to this education, I came to feel very patronized to find myself at every moment, be it watching TV, reading the newspaper, shopping in the supermarket, being told to do the most obvious things: 'eat more fruit', '5 a day'. Yes I am aware I should, however I will decide whether I want to, I do not want to read on the bag of carrots I just bought that three carrots are one of my '5 a day'. I guess the government's education initiatives to stress individual responsibility for health, are doomed to falter in the context of a national health system that makes people dependent and expects them to behave as (because treating them like) irresponsible children. People put themselves in a child's position, a dependent position. They make themselves receivers (of benefits, advice, care). They do not need to reflect and think for themselves. "I wasn't told not to so I did it", " Not my fault, not my responsibility. The company, the government, the council, the newspaper, the doctor should have told me, they should have taken care of me". Thus for example, when I go to the dentist in an emergency to politely ask for a temporary filling, the secretary fobs me off saying that they cannot help me the next three weeks as it is not an emergency as I am not in any pain. I am baffled, as the subject of pain has not yet come up. Now I know that next time I have to walk in crying demanding to see a dentist as I am in so much pain, then I might be helped. I am made to behave like a child. While feeling patronized I also feel robbed of my personal freedom (so stressed by the government) for example in choosing to see a specialist. This is impossible as they are protected by the GP gatekeepers, whose standard procedure 'come back in three weeks time' is indeed a cure-all. Either the problem has gone, or it is manifesting itself so badly a specialist visit is warranted, or thirdly the problem has gone together with the patient. From the cradle to the grave.

The Times, 9 December 2003, lead article on the Comment page, by Libby Purves, mother of two teenage sons:

> **"What can we do about the hell of being 16**
>
> *Dark clouds hover over Western modern adolescence (...) Adults always tend either to demonise teenagers – which satisfyingly compensates us for being old and cross and sagging- or else to offer them patronising little verbal pats on the head. It is useful, from time to time, to step back and think what it is like to be them. This is a good day to do so, because the British Medical Association produces a report on adolescent health in Britain.*[24] *It should be sobering reading because most of the threats to their lives are directly associated with the way they lead them. A lot of the facts are well-known: 20 per cent of 15-year-olds are obese, numerous girls are so scared of obesity that they are anorexic, a quarter of 15-year-olds smoke, a third experiment with cannabis, youthful cocaine use is increasing, and so is suicide. Promiscuity rises; Chlamydia infection (which causes infertility) has trebled in six years. We have the highest teenage pregnancy rate in the developed world. And that is before you get on to the binge drinking: under-16s drink twice as much as their peers ten years ago, thanks to sugary, fun-packaged Alco pops. Cirrhosis of the liver is turning up in people well under 30. We have already had Sir Liam Donaldson, the Chief Medical Officer, warning that many of today's teenagers will die before their parents. Now Dr. Russell Viner, of Great Ormond Street Hospital and University College London, is quoted as saying: "It seems that adolescents are the only age group whose health is actually getting worse... the report paints a bleak picture." (...) What strikes me most about the indicators of unhealthy, unhappy adolescence is the common thread running through them. These kids are not having fun. Their indulgences are not a symptom of jollity. Drinks, drugs, loveless promiscuity and bored overeating all tie in with depression. (...) The question "What's the point of anything?" occurs ever more frequently. You look for human comfort, but your parents are preoccupied with work or the process of divorcing one another. Perhaps you just lost touch with them, sometime between 11 and 13: once they didn't need to guard you every minute like a toddler, they forgot that you still needed them to talk to you, eat with you, be around. So you turn to your peers, and hang out (...) There is no single solution (...) no teenager is going to say openly: "I need you to love me and listen to me and appreciate my achievements and, if at all possible, stay together while I grow up", is he? (...) A steadier, kinder, less materialistic and more human family life could help, but let's not just blame the parents here. Consider education (...) don't blame teenagers; rather think of what they are looking for – love, human fellowship, knowledge, adventure, affirmation that the world has a place for them. They don't want to be angry and miserable and wheezing and hung over and infertile and obsessed with plastic celebrities at the expense of reality. We have to look around at family and neighbourhood and nation, and try, little by little, to make it sweeter to be sixteen."*

[24] The findings in this report are not new, see also Hardy on the BMA report of 1999 concluding that: "the children of Britain's poor were among the unhealthiest in the developed world and were destined to become illness-prone adults" (Hardy 2001: 172).

The above article summarizes perfectly how I have seen adolescence portrayed during three years in Britain, in newspaper articles, television documentaries, ads, soap operas, films, and in interviews with parents and health carers. It *is* the public discourse on adolescence in Britain. It touches upon many themes running through this thesis, all linked to adolescence: health, behaviour, and relationship with parents. The article disturbs me for the same reasons as the discourse, (adults talking about adolescents), does. Firstly because it accepts without questioning stereotypes as facts, 'adolescents *are* a certain thing and *do* certain things'.[25] I mind the matter-of-fact tone: stating that it is very normal that teenagers do what they do and are what they are. The grimmest picture is painted and while indeed those cases exist, there must be at least as many adolescents that are not like that. Secondly because of the issue of responsibility: 'we should not blame teenagers'. Again I find this a gross oversimplification. According to the author, the cause lies with the parents, but "let's not just blame the parents, let's also blame the education".[26] The author's tune sounds similar to what I picked up in the diabetes setting: 'No one in particular is accountable, instead it is the system that fails teenagers. We can remedy this by accommodating young people. We can soften this 'hell' by making things fun for them, not so much motivating or enthusing them towards something, but rather by winning them over'.[27]

---

[25] Articles like the present, oversimplifying the situation, causes and solution, only contribute further towards the 'medicalization of adolescence' (seeing adolescence as a medical condition), and it thus does not leave room for critical questioning or starting afresh. I stress this essentialist view of teenage behaviour as it will come back later in this work (Chapter 1) when describing the clinic consultations and contact between health carers and young people.

[26] This links to what a primary school teacher in Scotland told me in response to my quizzing questions. She related how parents expect the school to 'educate' (not just scholastically) their children, and how parents blame the school for everything that is 'wrong' with their children. She gave the example of Attention Deficit Disorder: parents do not realize their child is hyperactive because they actually never sit down and talk to their child, they expect the school to deal with it. I surmise that it seems that some parents seem unaware of certain practices that make you a parent. You never *are* a father; you become a father (or rather, you *do* a father). This is reminiscent of Overing's description of the Amazon Piaroa's 'performative' society, where the act establishes the relation: you are not married by ritual/ ceremony, you only truly become husband and wife by living together and acting as husband and wife (Overing 1996).

[27] In the diabetes context for example, this was apparent in offers that had nothing to do with the illness just to make young people come to clinic. A meeting for young people on pumps would be held at Pizza Express, with free pizza, 'it has to be fun'. Some clinics held an action that when you hand in 20 used blood test strips you get a free cinema ticket. 'The system' is also present in more general discourses. For example in his inaugural lecture Huw Davies, professor of health care policy and management at St Andrews University (23-04-03) mentioned how the care shortcomings in the NHS today were 'system problems', "not an account of bad people who don't care. Hence the solutions lie in the system, not in an exhortation of people." While I do not deny that the system is part of things, I frequently noticed the tendency (and convenience) to point to 'the system' as cause and solution for everything.

While I disagree with an essentialist view of adolescent behaviour, I do hold two essentialist views of young people myself. One is the biological one, the fact that they are a body, I will come back to this in the next section on diabetes; the other is a psychosocial one, the fact that they are growing up, becoming.[28] Thus, although throughout this dissertation I call the young people 'young people', as they do not like the term 'adolescent', in this section I do use the term in order to stress the 'becoming' part of them, the 'growing up' that I see as an essential aspect of their lives.[29]

Growing up in Scotland happens fast. The professional discourse of teachers, health carers and counsellors on adolescents in Scottish society today aims to empower adolescents at an early age (12) by emphasizing their autonomy and rights.[30] Growing up fast is not only a cultural value (independence, personal freedom) but also a social necessity. The nuclear family (two parents and children) has become an exception in Scotland, being replaced by single parents or newly combined families.[31] The young people are indeed 'independent', but without a safe place in which to experiment through trial and error, without a safe time zone in which to grow towards an autonomous person, able to make informed choices and decisions. No time or place to practice, it is for real. They live and act in the here and now, with full consequences for the rest of their lives. For example having a baby at the age of 14, taking drugs at 15, quitting school at 16. The problem is not that they live in the here and now, the problem, and yes it is a problem, is that there is no one around to keep in mind their future.

I recall my essentialist view of young people concerning their psychosocial development.[32] Growing up in a caring environment, guided and supported by adults,

---

[28] Of course we are all always becoming, through our actions, other people and things. However, here I stress that young people do an extra degree of becoming, with more need for protection and guidance.

[29] The term 'adolescent' has in social science literature often provoked a rejection of the 'becoming' implicit in it, instead of stressing the 'being' of young people in their own right (as mentioned before in the Introduction). Alison James (1986) starts an article on adolescents thus: "In contemporary British society being 'adolescent' means 'being nothing', 'having 'nowt to do' and 'nowhere to go'." She sees this self-description by adolescents as indicative of the liminal stage society puts them in by separating them both from 'child' and 'adult' worlds (James 1986: 155-156).

[30] For example, Millness social services sent a letter to a 12-year-old patient suffering a problematic home situation that she "should be able to take care of her own diabetes now, as she was already 12" (personal communication by indignant Millness diabetes nurse specialist Jane).

[31] McCrone 2004b: 40.

[32] I stress that this is in the context of modern Western society. Of course young people are 'beings' with agency, consciousness, creativity and sense-making capacities. I do not feel that stressing their biological

usually parents, who safeguard the future when young people are too busy living for today. While I would call this 'caring', in Millness it is often called 'patronizing', which together with its variant 'nagging', is a very dirty word in these days of empowerment. In the absence of parents or a nuclear family, it seems the caring role is taken over by the wider society, by professionals: health carers, teachers and counsellors.[33] —Is this a new form of 'reliance' on the state and the community spirit of Scottish society?[34] The approach taken by these professionals focuses on support, understanding and listening to the young people. At the same time, just like we are being told to eat '5 a day', parents are also being taught to listen to their children. The 'art of listening' is indeed a popular topic of the government's health education initiatives. In the frequent HEBS (Health Education Board Scotland) television ads that aim to sensitize the public to social ills like diet and smoking, parent-child relations are a recurrent topic. The stylish black and white ads stretch our curiosity by their length and their obscurity about what they are trying to sell, we see people doing things, but where is the product? No need to worry, at the end the message is spelled out. For example:

> *Mum is driving her young son home from a birthday party, he is chattering away about the games they played, what so and so said, what he liked, mum nods —*

---

and psychosocial 'becoming' diminishes any of that. On the contrary, it gives it more importance and respect, by ensuring that their agency is also there in the future.

[33] For example in Millness, The Corner is a famous place for support and advice: a drop-in place for young people to hang around and receive advice on drugs, contraception, and pregnancy.

[34] Only now I realize that I have encountered yet another of my preconceptions, a normative view of family life with parents caring for their children until they are ready to stand on their own legs. As Millness is in the Western 'modern' world I started from the 'norm' in 'Western society' (caring parents) to look at Millness. Not finding the same practice I took it as a lack and deviation. Like with my puzzlement on diet, again I wondered: when did it all change? Is the answer similar to that to the diet question: namely parents never stopped taking care of their children, things just always happened in another way. Thus I need to look at it differently: how *do* adolescents grow up in Millness, what are the mechanisms in place, instead of focusing on the cogwheel that is supposedly missing in the mechanism. What follows is a wild speculation that would make any historian cringe, though as it helped me in trying to deal with my astonishment, I mention it here. Perhaps there never was this strong family spirit in Millness, rather a community spirit? I refer back to the 'birth' of convenience food when mother went to work in the jute or jam factory in the second half of the 19th century. From then on, there was no time to cook, let alone spend time with the children, which also might never have been a habit, as seeing children as beings in their own right and not 'small adults' is a luxury —note that this differs from the 'becoming' debate on adolescence. Philippe Ariès writes on the modernity of the idea of the family; he sees the modern concept of the family (with privacy) as originating in the middle classes, in the 17th century. The lower classes kept their preference for crowds. To Ariès sociability was incommensurable with the concept of the family; one could only develop at the other's expense (Aries 1962: 407). A detail: the original title of Ariès *L'enfant et la vie familiale sous l'Ancien Régime* translates in English as *Centuries of Childhood*. Just as 'Ancien Régime' is dropped, since irrelevant for Britain, 'family life' has also disappeared, while in the introduction Ariès mentions clearly how his book studies the history of the idea of the family.

cue to the same mum, still driving, but now with grey hair and wrinkles, her now teenage son is still talking, about this girl he really likes, mum listens and smiles. The screen goes black and a white text appears: "Listen to them now and they'll talk to you later".[35]

HEBS ad 15-02-02

Though hearing it so often during fieldwork, but refusing to accept what I took as an exaggerated generalization, it is apparently taken as a fact that young people do not speak to their parents, as they nag. Instead young people talk to their peers and when in need, to professional health carers, or not.

4. Diabetes

A newspaper shop, the assistant is filling the shelves with sweets. A woman is drifting between the isles, she gurgles, makes choking noises: "chchchchchc". The assistant looks up, sees nothing, continues. The woman chokes again, comes up to the assistant, and implores him: "I'm dying, I'm diabetic, I'm hypo, I need some chocolate." The assistant urgently feeds her a Crunchy bar, the woman gobbles it up, says: "fizzy drink, fizzy drink", the assistant hands her a Sprite. Then the woman starts shaking, jumping up and down: "I'm hyper, I'm hyper, the only thing that can save me now is cigarettes..." The assistant asks which ones and hands over a packet of Marlboro. "... and a magazine..." The assistant enquires: "Cosmo? She?" — "Vogue". The woman thanks the shop assistant for saving her life and walks out with cigarettes, magazine, drink and chocolate. The shop assistant turns to other assistant off screen: "This woman was diabetic. I saved her life. I always wanted to be a nurse."

Smack the Pony sketch, Channel 4, 15-02-02.

[35] Thus there are parents who do not listen to their children and they need to be told? I mind most about the ad how it portrays as the only reason for listening to your young son's 'boring' stories the pay off that he will talk to you when he is 15. At least the ad does not stretch the viewers: you too can achieve this. The difficult and unattractive (since not practiced, or it is just a lack of time?) practice of listening to your young children, seems to only consist of performing the occasional nod while driving the car, keeping eyes safely on the road. You do not need to make extra time, or imagine, sit down at the table and give full attention; you can do this while doing something else, for example the school run. Just like those pelvic floor exercises you can practice unnoticed while queuing at the bus stop. Why am I reminded of this lady in Kenya, dutifully sweeping her house every day with a condom over the broomstick, as this is, they taught her in the health centre, how to prevent contracting AIDS?

In this section I mention Scottish policy, and biomedical and psychosocial discourses on diabetes. I do so because of the essentialist view I hold of adolescents. Young people are, among other things, a body. When this body is affected by a chronic illness, with behaviour and treatment impacting on later life, I find it essential to point out the biological 'facts' —a word that makes me duck my head in this minefield that is anthropology— of the illness.

4.1 "Diabetes: a Priority for Scotland"[36]

The website of Diabetes Scotland opens with a gloomy picture:
"The incidence of type 1 diabetes in Scotland is 24 per 100.000 per year in the under 15 year old population and it is thus one of the highest incidence areas in the world. The disease is becoming commoner at a rate of around 2% per year and we have no idea why this is."

Of today's 150.000 people with diabetes in Scotland, 2000 are children and young people (<15 years).[37] Diabetes, a chronic illness with possible serious health consequences, presents an immense cost both to people's lives and government resources.[38] Thus in 2001 the Scottish Executive launched the 'Scottish Diabetes Framework', to provide Scotland with a strategy for diabetes care. This strategy centred around collaborative care (collaboration between patients and doctors), which builds on the 'Expert Patient' concept launched previously by the Department of Health. 'Expert patients' are not mere recipients of care, but become "key decision-makers" in the disease process: "by ensuring that knowledge of their condition is developed to a point where they are empowered to take some responsibility for its management and work in partnership with their health and social care providers, patients can be given greater

[36] Title used in *The Scottish Diabetes Framework* (Scottish Executive Health Department 2001: 11).
[37] Scottish Executive Health Department 2001: 11. See also the results of the Diabaud2 study at www.diabetes-healthnet.ac.uk/children/facts/diabaud.htm. Globally, an estimate of 140 million people have diabetes, which according to the WHO will rise to 300 million by 2025 (International Diabetes Foundation website: www.idf.org).
[38] Diabetes is the fourth cause of death in the UK and accounted in 2002/2003 for 5% of the NHS budget, over £320 million (Scottish Executive Health Department 2001: 13).

control over their lives".[39] This patient-centred care puts the patient central, both as receiver *and* manager of care: a clear manifestation of the government's stress on individual responsibility and lifestyle.

Yet, on the way home from the official launch of the *Diabetes Framework*, Dr. John, head paediatrician of the Millness team, asked what I made of the meeting. While I expressed my surprise and enthusiasm over the 'holistic' approach by medical professionals, he put me firmly on the ground:

> "This is a lot of political chat. All this talk about 'self care', 'empowerment', 'give patients more education and information'. For all this you first need nurses and doctors to spend time with the patients to educate them. So it is mainly a political public image and will very likely not be realized for lack of money. Already there are not enough resources to do all the work and there won't be more money available."[40]

While John's comment already signals the huge discrepancy between policy discourses, findings, recommendations and practices in the medical diabetes world, I first turn to what biomedical and psychosocial discourses tell us diabetes is and means.[41]

4.2 Diabetes[42]

---

[39] Department of Health 2001 *The Expert Patient*: 5. Note the 'management speak': 'management', 'partnership', 'care providers': granddad with his sugar problem cannot just go to see the doctor, he now needs to become a manager, and enter in a partnership with his care provider.

[40] In fact, at the meeting the national manager of Diabetes UK mentioned how a patient-centred care model meant a need for a culture change and a focus on interpersonal relationships "bringing in what social and cultural anthropology looks at". Alex Greene told me this kind of talk was new. Five years ago health carers would not include interpersonal relations and patient background in their conference talks, but instead discard this data as 'just stories'.

[41] True to my essentialist biophysical and psychosocial view of adolescents I take these discourses as substantive. I spent the first year of fieldwork mainly reading through medical (*Diabetes Care*, *Diabetes UK*, *British Medical Journal*) and health psychology journals to build up as complete a picture as possible of what had been researched about diabetes in young people. Getting to know the field. Then why do I funnel three ring binders of 'adolescents with diabetes' articles into 400 words? Several reasons. This is not the place for a literature review, certainly not on medical and psychological literature. Secondly, over the years, presenting my research, I noticed that my anthropologist audience was not interested in the medical aspect. Ironically I could talk to medical audiences about the anthropological aspect of diabetes (probably because I have nothing else to tell them). Thus I consider my kilos of annotated articles on diabetes as part of my methodology, something I jumped into and digested, and can now relate here in a very concise form.

[42] I base this layman's description on data in the *Scottish Diabetes Framework 2001*. See also Appendix 2 for more information (from the webmd website) on Type 1 diabetes and how insulin works in the body.

Diabetes occurs when the pancreas does not produce enough insulin, a hormone our bodies need to transport glucose (sugar) obtained from food from the bloodstream into the cells where it is converted into energy. Without insulin, there is a build up of glucose in the blood (hyperglycaemia) that damages the blood vessels, and which over a sustained period of time can lead to serious complications such as damage to the eyes (which can lead to blindness), damage to the kidneys (which can lead to renal failure), damage to nerves (which can lead to foot ulcers and lower limb amputation). Diabetes also puts people at a higher risk of developing cardio-vascular disease.

Diabetes is treated by administering insulin to the body, through injections by pen or syringe or through an insulin pump. It is important to administer the correct amount of insulin the body needs at certain times, otherwise there is either too much free sugar in the blood (hyperglycaemia) or too little (hypoglycaemia). While extreme cases of both are easily detectable and have immediate physical effects (feeling 'hyper' —moody, rushed, blurred vision— or feeling hypo —lethargic and fainting), more moderate hyper states are not so detectable, yet are to be avoided, as sustained over a certain period of time they lead to the complications mentioned above. Clinical studies have shown that keeping the blood sugar levels 'near normal' (as a non-diabetic person), called 'tight glycaemic control', diminishes the risk of later complications. 'Tight control' is achieved by monitoring blood sugars at certain moments (x4) throughout the day through blood tests (finger pricks), and by deciding the insulin dose on the results of that measurement and future food intake and activity. Glycaemic control is expressed in the HbA1c (glycosylated haemoglobin) level, which shows the average amount of sugar in the blood over the last three months. While daily blood sugar monitoring is done by a simple finger prick, this lab test is performed at the diabetes clinic. As blood sugars travel up and down during the day, the HbA1c value gives a good idea of overall blood sugar levels, and thus of a person's diabetes control. Hence the HbA1c level, a measurable value indicating the patient's health and diabetes management, is central in the clinic consultation. It forms the base to decide whether management routines, type and frequency of insulin injections should be adjusted. Target values of HbA1c levels indicating 'good' control vary across centres and countries.[43] In some centres (e.g. Brussels) a 'good' value for diabetic patients is

[43] A non-diabetic person has an HbA1c of around 6.4.

between 6 and 8 (not too much sugar running free in the blood, but also no risk of too little sugar which would result in hypos) and from a value of 9 the patient is hospitalized in order to bring the level down. In Millness, adolescent HbA1c values range from 7 to 11, with some as high as 13 or more, and 9 being common.

A multitude of studies mentions that the way to 'good control' does not so much depend on the technical type of therapy (meaning number of injections, type and dose of insulin), but rather on the support package offered with it: commitment, flexibility and a focus on the individual.[44]

4.3 Diabetes in Young People: a Challenge

" *The overall glycaemic control of diabetic young people in Scotland (...) places the majority at a high risk of the complications of diabetes in adulthood.*"

Scottish Study Group for the Care of the Young Diabetic (2001: 239)

"*Young people with diabetes have always been considered a major clinical challenge and a test of all the skills deployed in clinical care programmes.*"

Dr. John, head of Millness Paediatric team[45]

"[D]uring adolescence there is a marked decline in metabolic control (...) this poses health care professionals and parents with numerous challenges."[46]

---

[44] For example, the already mentioned Diabetes Control and Complications Trial (1982-1993) showed how intensive therapy gave better glycaemic results than conventional therapy (DCCT 1995). The trial in a nutshell: the research followed 1441 patients, one group assigned to insulin pump therapy, the other to daily injections, over 6,5 years. Over these years the appearance and progression of complications were regularly assessed. In the trial intensive therapy comprised: initial hospitalisation so the patient became part of the team (which set out to achieve a certain goal), continuing management (first weekly and then monthly), minimum four blood tests a day and intensive diet management (each patient has his individualised plan to reach the glycaemic goal). The positive results of the intensive therapy were due to two aspects. Firstly the therapy was focused towards achieving one specific goal: glycaemic control as close to the non-diabetic range as possible. Secondly, the health care team was flexible and willing to anticipate and meet the needs of the individual.

[45] Greene 1996: 563.

[46] Skinner et al 2000: 26.

Adolescence is indeed a particularly critical time for young people with diabetes, as the period when they establish the self care behaviour that will stay with them for life, is at the same time rife with general developmental and diabetes issues.[47] For example, in teenage years the insulin regimen changes in response to hormonal development, an emphasis on monitoring diet and weight may lead to eating disorders, and a busy social life sometimes means skipping insulin injections.[48] This decline in self-care results in poor glycaemic control, with implications for health later in life. In other words, diabetes in young people is not for free.[49] The deterioration in self-care behaviour during adolescence presents a challenge to health care professionals: how to encourage young people to take up self-management?[50] How to influence their behaviour towards a more positive health outcome? Hence the rich gamut of psychological research on adolescents with diabetes.[51]

Psychologists claim that self management can be influenced by behavioural interventions: by investigating psychological aspects they can not only *understand* why patients respond to their diabetes in a certain way, they can also try to *adapt* their response towards a more favourable health outcome. Psychologist Skinner and colleagues (Skinner 2000) give an extensive overview of the psychological research to

---

[47] See for example Wolpert & Anderson, who in the editorial of *Diabetes Care* call for a new treatment paradigm for young adults with diabetes. This should centre on a collaborative care model, a partnership between carer and patient in which realistic treatment goals are established, so as not to miss this window of opportunity (Wolpert & Anderson 2001).

[48] Concretely for Scotland, a 1997 study at Millness Hospital found the amount of insulin actually dispensed by pharmacies significantly smaller than the total amount prescribed by doctors, showing that many adolescents failed to take the insulin prescribed to them (Morris 1997).

[49] Greene 1996: 563. As concluded in the DCCT report: "intensive therapy effectively delays the onset and slows the progression of diabetic retinopathy, nephropathy and neuropathy in patients with type 1 diabetes" (DCCT 1995). This seminal research finally provided physiological proof that intensive management with the goal of keeping the HbA1c close to normal did have a positive effect on long-term complications. In today's 'evidence-based' medicine, where health carers can only prescribe treatments to patients if there is scientific proof that they work, this was significant. It cemented the importance of taking diabetes management of children and young people seriously, as treatment in the early years did have effect on later years. Before the DCCT, health carers might have thought management in young people shouldn't be too strict, diabetes was already difficult enough to cope with.

[50] Note that while health carers call adolescents a challenge, I would rather call diabetes a challenge for the adolescents.

[51] I was struck by the amount of psychosocial research on diabetes in adolescents I encountered during my journal browsing. See Hampson & Skinner (2000) for a review of 64 empirical studies on behavioural interventions for adolescents with diabetes, with an evaluation of their effectiveness in improving self-management. The studies reviewed show a wide variety of interventions: skills training (45% of the studies), family-related interventions (25%), dietary interventions (20%) and problem-solving interventions (20%). Some of the interventions were theory based: 20% on family therapy, 14 % on social learning theory and 8% on behavioural principles. These theory-based interventions had far more success than the others. Significantly most efficient studies are those conducted in specialised diabetes clinics, which require commitment from all (team, patient, and family).

date.[52] Investigating which factors favour good diabetes self care in adolescents, studies found no significant relation between diabetes knowledge and practical skills and self-care. Thus, adolescents may *know* what and how, but will not necessarily *act* accordingly. In contrast, both personality factors (mature ego development) and coping skills (coping with life and illness) do bolster good self-care. What about the impact of the social environment (family, peers, health care professionals) on diabetes self care? Family support and low levels of conflict in the family were found to have the most significant correlation with good self-care.[53] This confirms the findings on general adolescent development, where parental involvement is also the "single most important predictor of positive adolescent outcomes" (Skinner 2000:40). Peer support was also found to be important, but only in combination with family support. Young peoples' social life comes before diabetes management, thus they may manage their diabetes but not at the cost of their social lives. Studies on the relation with health care professionals showed, unsurprisingly, that when adolescents liked their doctor or found her to be motivational, they would better manage their diabetes. Skinner recommends that the most important aspect for health carers is to maintain contact with their patients and to respect that diabetes is not the main part of their lives, diabetes should not be the be-all and end-all of the consultation. The goals set for management for young people should be made with them and should be realistic. There is no point in forcing something upon them that does not fit their own priorities or lifestyle. He concludes that the psychological research suggests it may be wise to temper the (fashionable) push towards adolescent responsibility, as lack of parental input and too big responsibility on the adolescent often leads to worse glycaemic control.[54] Only when the adolescent is ready and asks for more responsibility should it be considered. Likewise prominent health psychologist Barbara Anderson points out the value of a parent-adolescent partnership in managing chronic disease. She mentions current psychological development theories where the adolescence period is seen as a movement away from dependence on the family, *not* towards independence, but *interdependence* on the family. This requires that adolescents distance themselves emotionally from their parents and "that there is a

[52] Both Skinner and his colleague were laterally involved in the Millness Paediatric team.
[53] "[P]articipants from balanced families were in significantly better control of their diabetes than those in the disturbed range" (Skinner 2000: 39).
[54] "The greater responsibility taken by the adolescent with diabetes and the less parental involvement, the worse their control"(Skinner 2000: 39).

reorganisation in which family members renegotiate responsibilities and obligations" (Anderson 1999: 719).[55]

4.4 Guidelines and Variations

The plethora of biomedical and psychosocial studies on diabetes in young people have led to the publication of national and international guidelines for diabetes care in the young.[56] Most prominent are the *Consensus Guidelines* published in 2000 by the International Society for Paediatric and Adolescent Diabetes (ISPAD). The authors stress the need for guidelines as there are major variations in childhood diabetes care worldwide. This concerns differences in acceptance of diabetes as a major chronic disease of childhood, in provision of resources, management strategies, outcomes and cost-effectiveness. The 125 pages guidelines, bundling a consensus of 'best practice recommendations' from around the world, make education the keystone of diabetes management: "Successful education not only instils knowledge, it must also empower and motivate the young person to use knowledge and practical skills in problem-solving and self-management" (Ispad 2000: 27). The authors recommend that multi-disciplinary diabetes care teams (paediatrician-diabetologist, diabetes specialist nurses, dietician, social workers, psychologist) for young people should be based in regional 'centres of excellence'.[57] Psychosocial issues should be recognised as the most important influences on the care and management of diabetes. Adolescents should have special facilities where they can negotiate goals and priorities, can discuss emotional conflicts, and where they receive education that promotes independent, responsible self-management.

---

[55] Anderson conducted a successful study aimed at maintaining the parent-adolescent teamwork without increasing diabetes-related family conflict. To this end parents were increasingly involved with diabetes management tasks, like administrating insulin and testing blood glucose. Despite this increased involvement, diabetes-related family conflict decreased (Anderson 1999).

[56] For example in Scotland, the already mentioned Scottish Diabetes Framework (2001) and the SIGN guidelines (Scottish Intercollegiate Guidelines Network) for diabetes. The original 6 SIGN guidelines for diabetes were published in 1996-1997. These guidelines have been widely accepted by all health care professionals in Scotland, and are frequently reviewed. SIGN 55 is the most recently published (November 2001) review of all diabetes related guidelines (www.sign.ac.uk/ guidelines). It was reviewed in 2005 with recommendations for areas to be updated.

[57] The diabetes centre at Millness Hospital is a 'centre of excellence'.

Notwithstanding internationally published studies, guidelines and policies, there are significant differences between centres, both in diabetes care and outcome. What is particularly relevant for this present work is that the comparative studies highlighting these variations on the base of biochemical 'evidence' suggest looking for an explanation in social and cultural factors (such as approach to care), as all measurable variables (location, amount of resources) do not provide an answer. This means two things. First, that between guidelines and policy recommendations there remains ample room —in what I had presumed to be a strict medical setting— for personal styles and philosophies. Usually this is the philosophy of the head paediatrician of a centre, in agreement with the rest of the multidisciplinary diabetes team. Second, that it is particularly relevant to study these approaches to care, the social and cultural factors colouring them, and to study these comparatively.

4.5 The Hvidøre Study

In 1997, the international Hvidøre Study Group conducted comparative research on childhood diabetes to find significant differences in glycaemic control between centres in Europe, Japan and the USA.[58] Discarding both geographical factors and the organizational structure of the clinics as explanation, the authors suggest there may be "cultural or socioeconomic differences in the choice of treatment regimen among the countries that influence the glycaemic level"(1997: 719). A follow up study in 2001 found the same persisting centre differences and again states they are not explained by type of insulin therapy but that an answer should be found in "differing attitudes of the diabetes team and/or differing degrees of patient empowerment (...) factors such as the attitudes of the treatment teams, self-care behaviours, educational models or patient satisfaction may be more directly related to outcomes than insulin regimens" (Danne 2001: 1346).

[58] Mortensen et al 1997 and Danne et al 2001. The study compared the metabolic control of 2873 children over 18 countries (Europe, Japan and North America). The differences could not be explained by geographical factors (no regional patterns nor significant differences between centres in the same country), nor by a difference in the type of care, since all participating centres offered intensive therapy by a multidisciplinary team.

Differences in outcomes are not only salient between countries but also in the same country. Thus while over the last 20 years most Paediatric centres in Scotland (and England) adopted the same 'best practice' model, centring diabetes care around a children's clinic, a Young Adult clinic, and yearly diabetes camps, it is important to keep in mind that centres differ and that the Millness diabetes centre is quite unique. In 2001 a study (Diabaud 2) investigating differences in glycaemic control in young people between centres in Scotland, concluded that the key factor causing the differences in results between centres is not *which* resources a centre uses, but *how* it uses them. [59]

How then does the Millness diabetes centre use its resources? In 1999 the diabetologists and physicians of the Millness diabetes centre published their views on the care of the 'diabetic teenager', emphasizing the ability of the health carer to listen to the young people.[60] A true understanding of young people's views and problems was more appropriate in combating the decline in glycaemic control than the conventional strategies of insulin regimen or imposing home blood tests. A deterioration in self-care was not down to, and thus not to be solved by, mere biochemistry. Instead psychosocial factors, such as eating problems, missing injections and fear of hypoglycaemia, played a major role. Thus the Millness carers listen to the young people and have learned from them that credibility and enthusiasm of doctors is important, together with continuity, in the form of a long-term friendly and trusting relationship with the doctor. When the carers asked young people in a previous research in 1987 what they would most like to tell their doctor, the unanimous answer was: "it isn't as easy as you think."

---

[59] The centre with the 'best' glycaemic control combined frequent (monthly) contact between patients and health carers with a rapid troubleshooting service, frequent changes in insulin regimen and the goal of a near-normal blood sugar level (SSGCYD: 2001).

[60] Newton, Connacher, Morris et al 2000. The research conducted by Alex Greene with the team (1997-1999), no doubt added to the health carers' insights and approach. In her dissertation (2000) Greene advocates patient-carer interdependence, stressing how and why health carers should include young people's social and cultural backgrounds: "[g]etting care right is, therefore, not just about being a good diagnostician but about being someone who can form relationships with young people and can be sympathetic so that they will want to look after themselves in the recommended way" (Greene 2000: 13). I will return to this approach to care in Chapter 5.

Not surprisingly, the Millness centre featured at the bottom of the league in the aforementioned international Hvidøre study: the blood sugar levels of their young patients were significantly higher than in other centres. When colleagues of centres with 'tight control' confronted the Scottish health carers with their centre's 'bad' results (whether in Boston, Yale or Brussels this fact was 'famous') their standard reply was: "But our quality of life results are the best." To which more than once I heard the critical colleagues respond along the lines of: "What quality of life? When they go blind and lose a leg when they're 20?"

Hence one of the lines of investigation I pursue in this dissertation, are differences in approach to diabetes care that may explain these discrepancies in medical outcomes. As in the course of this research I conducted fieldwork at four Paediatric diabetes centres that feature in the Hvidøre study: Millness (at bottom of league) and Brussels, Gothenburg and Boston, all in the top range.

* * *

PART ONE

DOING DIABETES

In the previous chapter I described the discourses underlying practices presented in this thesis. The red thread weaving through the following ethnographic chapters (showing these practices) is how both adolescence and diabetes are a construction. I thus aim to show —in practice— how discourse constructs. I show the uniqueness of construction in Millness by contrasting it with another way of doing diabetes, in Brussels. While Millness' construction seems obvious, as social and cultural ideas on adolescents and diabetes are taken as, and made to be, 'facts', one might suggest that in Brussels another type of construction takes place, taking the physical body as a 'fact'. While less notable, is it any less construction? Since using the term construction might wrongly imply there are such things that are not constructed —while all things 'happen', 'coincide', are done and performed— it might be better to show how it is concretely done. We therefore leave the media and the social science studies, to check into the medical setting of the hospital. How does the construction happen in clinic consultations, in the health carer-patient relationship?

The following five chapters portray people 'doing' diabetes.
In Millness, the main fieldwork site, we see and hear the health carers care for young people with diabetes (Chapter 1). Then we observe how the young people themselves live life with diabetes (Chapter 2). To highlight the specificity of Millness care we then visit a diabetes centre in Brussels, and are confronted with a totally different approach to diabetes care, both by health carers (Chapter 3) and young people-patients (Chapter 4). A discussion chapter (Chapter 5) reflects on the most striking differences between the two approaches, by putting them in a wider 'care' context.

But first we meet Charlie, a 16-year-old Scottish boy with diabetes.

*

Charlie

A Young Person With Diabetes

A council housing estate in Milgask, a small town near Millness city.[1] A sunny afternoon, 3 pm. I am here to see Charlie, a 16-year-old boy I met at Pinewood diabetes camp.[2] Charlie is representative of those teenagers the Millness diabetes team worries about, wondering how to make the youngsters manage their diabetes. Very negative at the start of the camp, towards the end Charlie became a 'character' of the group, a central figure almost. Over a period of eight days, he showed himself to be bright, full of initiative, an elegant Macarena dancer, caring for his fellow campmates, and even realising, after four days: 'I do swear a lot, don't I?'. Speaking proudly about his job in the local Spar, about his college course, he turned out to be a lot more than the morose adolescent he seemed at first.

I want to hear his opinion about the camp. I also want to find out how he sees and lives his diabetes. I don't know Charlie well but remember him vividly. A 'Scottish' adolescent with standard hairdo (fringe drowned in gel and draped over forehead), piercing in left eyebrow, 'fucking shiting' everything that was done or said.

So here to meet Charlie. But Charlie is not here. The house seems empty and no one responds to my knocks on the backdoor, which leads to the kitchen with the ironing board taking pride of place. The neighbours' backyards are full of hanging baskets, bright yellow and orange capucines, a birdhouse, tidy gardens. Charlie's backyard is a yard, a patch of grass with stone path leading to the kitchen door. The path is littered with sweet wrappers, plastic juice bottles, two forgotten bread-knives [*for gardening?*], a huge water-gun, other plastic toys strewn around. I get the impression of a deserted house, toys carelessly left in the garden by kids using the house as a 'camp'. I walk through a passage to the front of the house. A woman stands at the closed front door. I

[1] My personal additions, clarifications and thoughts are between [ ].
[2] See Appendix 1 for an extensive ethnographic account of my stay at Pinewood camp.

ask her if this is where Charlie Mackie lives? She responds that no one is home and that she'll try later, she goes off to the house next door. I decide to wait and sit down on a rock formation in the middle of the green plot surrounded by the estate.

The front yard is more depressing than the backyard. I wonder how come this house is so different from the others in the estate, and what the neighbours think of this scrap-yard. All other houses have fenced off gardens, trimmed hedges, flowers, and plants, washing on the line. All have an identical garden shed, which looks brand new and takes up half of the garden. Must have been a bulk offer. The gardens look cheerful, colourful and alive, families live there, they take pride in their home, take care of their garden.

Charlie's house is different. It looks desolate, no fence or garden shed, just the communal grass leading onto the front door. No name or bell or knocker on the door [*does anyone actually live here?*], no plants or flowers. Again the grass is littered with sweet wrappers and juice bottles, an empty tube of Hypostop[3]. Alongside the wall separating the houses next to the front door: a gas stove, a mountain bike, not locked, a helmet next to it, a skateboard, a scooter, a pair of socks, two tents in bags, a piece of sponge...all things which are in use, but out there for anyone to take, as if on a rubbish heap. This is probably what the neighbours use their sheds for.
Still waiting for Charlie.

I go through several scenarios: probably he's just late, he can be on any bus arriving; maybe he is home, he just doesn't answer the door, he is sleeping; he forgot, other researchers have told me it's quite common for adolescents not to turn up at an arranged interview, they just forget. This would be a first for me. It is possible, this boy is not the organised type, nor is his family situation. He lives with his mum and three siblings and when I called him on the phone to arrange this meeting he stopped talking to me to shout in the room 'will you bloody shut up I am talking on the phone'.
[*I think of my interviews in Belgium last month.*[4] *My appointments were arranged by a letter sent by the head diabetologist to the parents, and confirmed by a phone call with them. The parents assured me they and their adolescent child would be there, they wouldn't think of not 'complying' to anything coming from the diabetologist and his hospital. I remember another time in Scotland when a dietician, a nurse and myself are*

[3] Hypostop: medicine to rub on tongue in case of acutely low blood sugar levels.
[4] See Chapters 3 and 4.

waiting for an hour in the hospital for a girl who would be put on an insulin pump. Both the dietician and I have travelled one hour to get there. Three professionals waiting for a young patient to come to her appointment. Since nurses are used to patients turning up late, we wait diligently. After one hour the nurse decides to call the patient's home because the patient is normally punctual. The nurse comes back after her phone call: "Her little girl is feeling poorly so she had to stay home with her and decided not to come. And then she said 'I guess I could have called'". The nurse is astonished: the ease, the relaxedness, with which the girl doesn't even think of calling... 'I guess I could have called'....". The dietician says she's used to this, I mumble I am too, it doesn't matter. We all go our separate ways.]

Back to Charlie who is still not here [*because he has forgotten?*]; then annoyance comes up. However, he might also be home but having a hypo, suffering, unable to come to the door. That's the trouble with these young people, you never know whether they are just being lazy and 'kids' or whether something is wrong, related to their diabetes. [*They know this too and are not innocent of using it, like feeling low and needing a sugary snack 'chocolate please, or coke', not going to school, not doing sports, the list goes on.*] Thus my annoyance is out of place, maybe I have to feel sorry for Charlie. [*It is confusing not knowing the situation and thus not knowing the proper emotion for it. In a wry way this might resemble the young people's confusion: they often don't know whether they are high or low, can't trust their physical feeling to know their blood sugar level and whether they need sugar or insulin.*] Even worse, he could be in the hospital and his mum is there to visit him, that's why no one is home. By now the neighbour has come round twice 'no one around yet?' I have been sitting here on the grass for 30 minutes, writing in my notebook. I guess she doesn't know what to make of me, probably a health visitor or college counsellor obviously not being one of Charlie's mates. I decide that since I have waited so long I'll wait more, at some time someone is bound to come home. Then I can find out what happened or leave him a message, also showing: 'I waited for you for an hour, you are important to me, and your opinion too'.

A school bus passes on the nearby road, stops, and unloads kids. Two young girls walk in my direction, one girl enters a house, the other continues until she stands in front of me, licking a lollypop so bright yellow-pink I can taste it by just looking at it.

- "Are you here for ... ?"

[*I still have not perfected my understanding of the local accent.*]

- "I am here to see Charlie Mackie" I reply diplomatically, not showing I didn't understand her. She nods "he's my brother".
- "Do you know when he'll be home?"
- "He's in hospital, he went there with the ambulance yesterday."

I feel guilty of my bad thoughts, I should have known. We talk about the ambulance and what happened. Then she says: "I'll go in the house to see if he's back". She pushes the front door that was open all the time, comes out again: "No, he's not home yet".

An older blond girl arrives, fashionably dressed in suede jacket and jeans. Her sister? Her mother? I introduce myself. Her mother. [*She cannot be older than 33, later I learn she is 35, Charlie is 16*] She is just back from seeing Charlie in the hospital. All wound up, she is at her wits' end. As we stand on the grass she 'unwinds'. It all comes out in one breath.

" He's almost living there (Millness Hospital) now you know. He went in on the Wednesday, 'cause I could smell the ketones in his breath, he then discharged himself on the Thursday, started partying on Friday and all Saturday, and on the Sunday he had a massive hypo and had to go to Millness again. I've just been to see him. I wouldn't go and see him now, he's not really with it, but you can go and see him tomorrow, he's on Ward 15. Actually, you'll catch him at his best then, not dazed anymore and not on his way (to a new hypo yet). I also had a chat to one of the doctors of the diabetes team just now. I told them this can't go on like this anymore, he's in here (the hospital) all the time, something needs to be done, it's like out of his hands. And he's one of thousands of kids, he's not alone in this. The diabetes team should install some rules, be hard on him."

I am surprised at how Mum puts the ball completely in the doctors' court. Since it is now 'out of Charlie's hands' it's high time the doctors stepped in. She does not mention that she has tried and could not make a difference. It is as if she is out of the equation altogether, in Charlie's diabetes there's only Charlie and the diabetes team. Neither does she mention that it might be Charlie's diabetes management (e.g. whether or not he takes his insulin, the correct dose, whether or not he monitors his blood sugar and reacts with the correct dose of insulin) that is causing these unnecessary hypos. Her

explanation of why he keeps ending up in hospital is that he parties all the time, gets drunk and then has hypos. Thus the doctors need to have a serious chat with him to put an end to this all too familiar sequence of events. —Talking to Charlie later, I'll find he holds a similar 'simple' explanation for his frequent spells in hospital.

*

Today is the day after, when I will 'catch Charlie at his best' to quote his mum: not drowsy anymore and not yet partying again. On my way home from another interview, I stop at the hospital to see if he is still there and might like some distraction. He has been moved from Ward 15 (Intensive Care) to the less intensive Ward 1 —which, according to Charlie, houses men with either diabetes or heart problems. As I enter busy Ward 1 —chaotic to me as an outsider having to get used to machines on wheels, medical equipment and blue or white-coated staff everywhere— I ask a nurse for Charlie. She points me to the end of the wide corridor. Ward 1, Bay 3: not a room, just a space at the end of the corridor. No wall to separate it from the busy corridor with everyone walking past. The only privacy —visual, as no sound isolation on offer— can be obtained by pulling a curtain around the bed. Truly a 'bay', with six beds. The two patients at the end of the bay are lucky, their bed is next to the large window, displaying trees and grass and a beautiful sunset. With their curtain pulled they made a 'house', have some privacy at least on one side of their bed.

It's not hard to spot Charlie, the 'young one out' among five pensioners. He seems so out of place. The last, and only, time I saw him he was the rebel, swearing all the time, hair gelled up in spikes, a piercing. Now in his hospital nighty with pastel motifs —though personalised: his bare chest showing off two silver chains— his hair flat, he looks endearing.

He is sitting up in the middle bed, one arm resting on the bed with a drip (insulin and hydrochloride), the other picking at plastic food tubs (dinner ordered by the former resident of his bed a week before). He only realises I am here to see *him* when I am almost sitting on his bed. I tell him I was at his house yesterday and his mum told me he was here. He remembers our interview and apologises he could have called to let me know. [*So he did not forget after all.*] He is happy with the diversion and doesn't mind to talk, as he has nothing else to do. So he eats, I sit on his bed at his feet and we talk.

As we talk one man has trouble eating and is helped by his wife, the one next to us puts on his oxygen mask and breathes noisily. When I ask Charlie whether the food is nice, the old man in the bed opposite shakes his head and comments: 'he thinks it's terrible, says it all the time'. I realise this will be a conversation open to anyone who cares to join in.

When Charlie starts telling me how he loved the camp "it was brilliant, especially the activities" I reply that I am a bit miffed to hear that, since he was the biggest moaner "do we have to do this, can't we just stay here and sleep?". He laughs this away saying that was just him being awkward. In the mornings he wants to stay in bed, he was tired because they would have been partying all night.

What then was so brilliant about the camp?

"We went to the camp to be away from the rest of the world, to have a laugh, we were all gonna be healthy, like, nothing major happened to us (no hospital hypos) and still we had fun and drunk, and there was supervision of adults. Whereas at home I have my tea (dinner) and go out again, I'm never at home. It felt good being there instead of in the middle of nowhere [5]. The camp is to help diabetics find people, to tell diabetics there's more users in some age group that's got the same problems."

Did he learn anything about diabetes at the camp? He learned about different types of diabetes [people taking different types of insulin and different amount of injections], though he did not talk about that with the others: "That's just why you're there, you're there *not* to talk about it. We're at the camp to have a laugh and enjoy ourselves."

I mention that the camp costs a lot of money and, if it is only for them to enjoy themselves, I think there are a lot of non-diabetics who would also love to go on a camp like that.

Charlie: "But they don't need it. They can do what they want all the time."

Griet: "No, they can't do the activities, they don't have a kayak."

Charlie: "But for us, it was to give us a break, from the routine everyday stuff, a break when we don't have to worry about our diabetes."

---

[5] Rereading my notes I am puzzled: the camp *was* in the middle of nowhere, did I leave something out? I then realised that to Charlie, his daily life in a small Scottish town is the middle of nowhere, as he will often stress, while the camp to him was in the hub of things: people of his age, even better, with diabetes, doing things and having fun.

Griet: "Why do you not have to worry, and about what?"

Charlie: "'Cause you know what time you eat and everyone takes insulin, so you forget about diabetes. You still do diabetes (give injections) but at the same time all the others have to do it, so you're not worried about it. Like when we were going to the pub with everybody, you're not the only one who takes a sugar free drink and stuff, we all do."

Charlie went to the camp to have a break. By offering a safe and shared environment where similar young people look out for each other and where diabetes management happens almost automatically, the camp temporarily suspends individual responsibility for diabetes. This is a break from everyday life at home, characterized by continuous worrying about diabetes and remembering the management routine. Which in Charlie's case is still a simple 'two-injections-a-day' routine, morning and evening, since he leaves out all the other necessary management acts of four daily blood tests and adjusting his insulin dose accordingly. At home he does not have a routine, thus no frame where the diabetes routine can be slotted in. Once out of the camp and back in everyday life, it is him and his diabetes again, and he is on his own to manage it.

Charlie never tests his blood sugars: "There's no point. I can feel when it's high and so if I would test then there's no point cause it'll just tell me that it's high and I already know."

I tell him that when he feels it's high, it's probably very high, why doesn't he test so he knows how to react and keep his sugars more stable? He shrugs: "There's no point in trying to struggle through something, just play it your way."

Griet: "Why is there no point? You are often in hospital, you don't mind?"

Charlie: "It's not that I don't give a damn, about diabetes. I just can't be arsed."

I ask him he can't be arsed to do what? What would he need to do, so that according to him he would be taking care of his diabetes? While I am thinking of many things he could do to make a start of managing his diabetes, such as testing blood sugars, keeping a test diary to monitor his results, taking injections on time and in the correct dose, doing exercise, eating a healthy diet... to my surprise Charlie comes up with one simple thing: "The eating: not eating chocolate. I eat like four chocolate bars a day, I get these cravings for chocolate and I can't stop. I don't even enjoy eating it, I enjoy the

first one, but when you're on the second one it's just (eating for the sake of eating)." For Charlie, the problem with diabetes thus seems to materialize in chocolate.

When I ask him if he is in control of his diabetes he says he could be if he wanted. He was in control for a year, he was living with his dad at the time " ...and he lives out in the country, no shops, nothing. I was in control then. Yes, I hope to be in control again, but then I'm onto my second chocolate bar and...."

I confront him: "So you don't really want to, you say you could if you wanted, but you're not, so is that because you don't want?"

He replies: "I *do* want to be in control and I can, I *know* I can, but when I'm at the shops and your mates are buying all these chocolate bars. I *hate* Scotland, I really hate it, it's boring, I want something different, go somewhere else, even England. I've lived in Milgask all my life, there's nothing to do, half of the pubs, either my mum works in them or her friends. (...) (I want to) enjoy living, have a fresh start, I'd really like to live a proper routine. I can't do that in Milgask. It's so boring, I don't have a life, it's just boring [*Charlie goes to college two days a week, the other days he hangs around with his mates*] and I don't have real mates, half of them aren't really real mates, like, maybe I have two or three real mates."

I ask him what he would like to be in the future, like in a year's time.

Charlie: "I would like to be a holiday rep, in Greece, the nightlife; I'd love to party all night every night. I studied for that you know, I did tourism at college, I would have to go back and do a GCSE but... I'm doing engineering now. I'd also like to be a PE teacher; I love sports, swimming, football, roller blading."

I ask him about the worst scenario for his future.

Charlie: "In a homeless unit in Milness, no job, no money, and a druggie, with my mum [*I am surprised, until he adds*] she works there."

Does diabetes interfere with his plans for the future?

Charlie: "It's fighting a battle all the time, and sometimes when I can't, I can't be arsed."

Just as Charlie is clear on what exactly he would have to do to improve his diabetes (i.e. eat less chocolate) he is also precise on why it is so difficult for him to do

that, and even why he eats chocolate in the first place. It is because he lives in Scotland, where there is nothing else to do but to hang around, being bored, eating chocolate.
I remember at the camp that he said about some boys from England, who were at ease with their diabetes and had it under control, that it was "easier for them". During a pub visit these 'sorted' English boys told me they couldn't believe that the people struggling with their diabetes just said that it was 'easier for them' to manage it, as if they didn't have to work on it, that it just happened. I ask Charlie.
Charlie: "It *is* easier for them...down South it's easier. —*I ask Why? What's down South?*— They live in places where there's things to do (....) new things, places to go, things to do, sports —*I ask You can't do sports in Milgask?*— There's a sports centre but it's wrecked, and I can't swim there (...) A life, you can have a life (in other places). Like at the camp, I was healthy. —*What do you mean, healthy?*— doing all those activities, being out all day, doing the activities and the eating."
I confront him: "So the only thing that makes it easier for them to manage their diabetes is that they live down South?"

Charlie: "Yes."

Griet: "So if I were to take Phil for example (one of the 'sorted' English lads) and put him to live in Milgask, he would not be in good control anymore?"

Charlie: "No."

Griet: "So other things like family, behaviour, routine, don't come into it?"

Charlie: "No. Well, maybe family a bit..."

I feel for Charlie. He has many reasons why his diabetes isn't in good shape and why it is so difficult for him. And he can think of many scenarios when his diabetes would be better:
If he lived somewhere else, or if at least he had a car, if he had a job and a routine, if he was a PE teacher. The fact is, he is a bright lad. He could get a job and sort himself out. Though he seems infected with what I will encounter so often during fieldwork in Scotland: a kind of defeatism, a tiredness, not much to do, to enjoy, to get up for. His 'cannae be arsed' describes it perfectly. Having seen where he lives and hearing about his daily life, it is not so hard to understand. Though it only took a few days with peers and fun things to do to get him going, to make him care. The following two years when

doctors and nurses discuss a new treatment program or activities for young people, I will often mention his name. Nurses will compassionately shake their heads, calling him a 'lost cause'. So many people have tried, put in effort and time, and Charlie always quits. Nurse Catherine who has known him since he was 7, explains: "He can get all the support he wants, as long as his mum does not show him she cares, that's not enough. The only thing he wants is for his mum to say she loves him." Since he was a child Charlie has felt responsible for his mum who has known abusive boyfriend after boyfriend. He took care of her. He would like her to take care of him.

*

1

Millness Health Carers

"You just pray they get away with adolescence and come out of it without too many problems"

Dr. Caroline, paediatrician

1. The Young Adult Diabetes Clinic

Adam: [*picks up file*] "Ian..."

John: [*puts head in hands and sighs*] "Oh no..."

Adam: "This is one of yours John."

John: "Well I'm sharing him with you, and later, when he's making sense, I'll have him back."

Adam: "Ian hasn't got a clue, is quite cheerful though. Just came back from Magaluf where [*Adam puts on a low voice*] 'I took my evening insulin at 8 a.m. in the morning because I was having such a good time'."

John: "But he's a nice lad."

Alan: "Except that he's a banana."

John: "He's a banana with a history. I think for a few years his mum and dad used to have a suitcase packed at the bottom of the stairs so they could do a runner."

Alan: "How?"

John: "Well, money claims, taxes, social services. A poor family. I feel for them. Ian will come good some day. I bet you 20 pounds, in a few years he'll be the one on committees and very involved."

Adam: "I think my money is safe."

[*laughter*]

Alan: "I'll just hold on to the cash shall I?"

[*More laughter*]

It is 6.30 on a Wednesday evening, the end of the monthly Young Adult Diabetes Clinic at Sevenhills Hospital, Millness. All patients have gone home. The consultation rooms are locked. The centre is deserted apart for the five doctors (Alan, Adam, John, Caroline and Alexandra) and the two nurses (Madge and Sally) who run the clinic. They are gathered in the waiting room to collectively discuss every patient who came that afternoon, and to decide on action for problem cases. Though all are tired and ready to go home, this is an important part of the clinic. As there is no fixed doctor for a patient, it is crucial that all doctors more or less know all patients.

The Young Adult clinic is a transition clinic, established to soften the switch from the Paediatric clinic, to the Adult clinic.[1] The Paediatric clinic is the first hospital contact for children with diabetes. It takes place every Monday afternoon in the children's outpatient clinic at Millness Hospital. You step into a bright waiting room with computer games, television, magazines and lots of toys. Children are playing, babbling, sometimes screaming. The place is bubbly and alive, full of activity. Friendly nurses, brightly animal-decorated consultation rooms, with children's seats and desks, drawing material and more fluffy toys. The children come and go to see the paediatrician with their parents, who mostly do the talking. The nurses' room is again an animal kingdom with smiling giraffes on the height measure, stickers for being brave and (anaesthetising) 'magic cream' in case of a necessary needle prick.

The Adult clinic is located more in the entrails of the hospital. The secretary's office screened off by a window, the waiting room a space onto which five doors of nursing and consulting rooms open. Chairs are arranged with gaps to accommodate wheelchairs. Magazines on a low table provide the sole entertainment. Compared to the lively crèche-like Paediatric clinic, the Adult clinic is a grave place. Regardless of the number of patients waiting, the room will be quiet, no one chatting, most patients are old, some on crutches, some in wheelchairs, some helped by a nurse. The nurses are 'adult' (as opposed to 'paediatric') nurses and the doctors are diabetologists or endocrinologists. They approach patients differently: mean consultation time is ten minutes, in which diabetes problems and complications are discussed. Patients usually come with exhaustive lists of symptoms (tired, out of breath, dry skin, twitches etc.),

[1] I will elaborate on the Paediatric clinic and its team, my major fieldwork location, in Section 2 of this chapter. I start this chapter with the Young Adult clinic in order to emphasise the particularity of the paediatric team.

although consultants will often retort these are not to do with diabetes and 'let's stick to the diabetes things'. Patients come in, the doctor goes over the diabetes checklist, a short chat, 'How are you?', 'We'll see you in three months'. The consultation lasts around ten minutes. In a morning clinic one doctor sees up to 15 patients. In the Paediatric clinic, paediatricians see about five patients in an afternoon. The careful approach in the Paediatric clinic becomes (mainly through time pressure, but also by differently oriented doctors) a swift performance in the Adult clinic. Next please.

To smooth the transition from the cosy Paediatric clinic to the more clinical Adult clinic, 20 years ago the 'Young Adult clinic' was established. This clinic caters for 'young adults', between the ages of 16 and 21.[2] It takes place in the Adult clinic, the territory of the adult diabetes team, which is significant[3]. Adult physicians and paediatricians, and adult and paediatric nurses run the Young Adult clinic together: a transition for both patients and health carers. The young people see familiar faces in a new environment. The health carers discuss the patients together and the paediatric team can lead their patients to the adult team. They decide on treatment together, and John, the head paediatrician, or Sally, the paediatric nurse, will fill in the adult physicians with the medical history and personal details of the patient. The paediatric team's caring approach contrasts with the more detached adult team which has a bigger case load and thus has less time for its patients. Once people are adults, I am often told, they take their own decisions in diabetes management and life.

In theory a patient visits this monthly clinic (every second Wednesday afternoon of the month, from 4 to 6.30, a convenient time for young adults, after school or work) every three months, as this is a good frequency to monitor blood sugar levels and to check whether the treatment regimen is appropriate. Some young people, though, might only come once every six months, once a year, or not show up for a few years. People who miss scheduled appointments (everyone is automatically scheduled every three

[2] The criterion being not so much age but schooling: as long as young people are in education, they go to the Young Adult clinic.

[3] Paediatricians seem to be at the bottom of the hierarchy in hospitals. As they deal with children, and all illnesses of children, it is thought that they cannot be very specialized in any. As a result they are not always taken seriously. Adult physicians are higher up and tackle serious issues. This hierarchy is visible in the centre, mainly in comments from paediatric health carers, on how they are treated by members from the adult team.

months) will be contacted and invited again. If necessary, a nurse will visit them at home.

I sit with Catherine on one such three-monthly visit. Catherine 18, bubbly, wild blond curls, diabetes for ten years has been coming to the Young Adult clinic for two years now. Sally, a friendly 36-year-old paediatric nurse calls her in the treatment room. As in the Paediatric clinic she weighs and measures her, writes her results down in her file, and she pricks her finger to draw blood to measure her HbA1c level (glycosylated haemoglobin: the average amount of sugar in the blood over the last three months). Sally has a chat with Catherine, she has known her for six years, asks her how she is doing at college, if she is feeling well. Catherine goes back to the waiting room. Today she does not have to have a picture of her eyes taken or her urine tested, both part of the yearly check up which she already had. Nor does she need a chat with the dietician, since she is happy with her (non-existent) diet and feels she does not need any advice. So she moves on to the second waiting room, waiting to see the next available consultant. This waiting room is a proper room, spacious, bright, one open door, through which people go in and out. There is coffee, tea and biscuits, a water cooler. Again a low table with magazines. Some panels along the wall with information on diabetes and smoking, diabetes and pregnancy, diabetes and drugs. Most patients will just sit and wait. Again, the waiting room is very quiet. People don't know each other. They are just here to see the doctor and will leave again. It is strange to see ten or more young people (aged 16 to 21) gathered in a room in absolute silence. Put each of them with any of their friends and they'd be chatting and giggling away.

After a 20-minute wait Alan (the senior adult physician and head of the Adult clinic), white hair, impressive posture, open white coat over a shirt and tie comes in the room. "Catherine Graves?" Catherine follows Alan to a consultation room. Alan closes the door. The room is dark and bland. Blinds cover the narrow windows. Neon light is on, the floor and walls are grey. From the carpeted and easy-chair waiting room, through the hotel style hall (decorated with soft focus wall paper, a patterned freeze and framed paintings with copper headlights) we have entered the medical realm. This is where serious things happen. No need for comfy chairs or carpet. The impersonal small room holds a desk with computer and papers and pens, three chairs, an examination bench which can be screened off by a grey curtain, the sink with ubiquitous antiseptic soap and instructions on washing hands and what to put in which of the different plastic

waste bags (sharps / chemical waste/ normal waste). On the wall colourful laminated posters inform us of types of insulin and spread of diabetes. As in the Paediatric clinic, the examination bench will only be used as an extra seat or place to put coats. This makes me wonder even more why these consultation rooms need to be so grey and dark, especially since almost nothing 'physically medical' happens. The chairs and desk are the only furniture ever used in the rooms.

Alan: "How are you doing Catherine?"

Catherine: "Not too bad."

Alan: [*looks at her blood sugar result the nurse took before*] "You've drifted up a bit Catherine."[4]

Catherine: "Have I, how much?"

Alan: "9.8. What are you doing now?"

Catherine: "College."

Alan: "What are you gonna do?"

Catherine: "I'm thinking of history, I really like history."

Alan: "What insulin are you on now?"

Catherine: "40 and 30, is that what you meant?"

Alan: "Yes. And are you good with your insulin?"

Catherine: "What do you mean?"

Alan: "Do you remember, some time you forgot to take it?"

Catherine: "No, I never forget, actually, now you mention it, this morning I was on my way out and realized I'd forgotten."

Alan: "And are you good with your eating?"

Catherine: "I'm better now, I used to think I was good, but I know I wasn't really."

Alan: "What's your binge eating now?"

Catherine: "Crisps, I love crisps."

Alan: "What variety?"

Catherine: "Cheese and onion."

Alan: "What make?"

Catherine: "Walkers."

[4] HbA1c parlance: 'going up' is bad (higher levels of sugar in blood, 'bad' control), 'coming down' is good (less sugar in blood: better control).

Alan: "Oh yes, Walkers are good. I love Walkers crisps. I suspect you went up because of your crisp eating. That's the only thing I'd say. Take a self-critical look at your eating, once in a while it would be quite nice to stop and think about your diabetes, and the eating is a pattern. It is very easy to keep on eating and grabbing. I'd quite like to see that HbA1c go down to 8% though."

Catherine: "Yeah, me too."

Alan: "You know why?"

Catherine: "Because it's never been there before?"

[*Alan takes a pencil and paper and draws a quick graph*]

Alan: "Complications start at 9, so for a little effort, to take it down, you could get a big reward. When will we see you again?"

Catherine: "When do you want to see me again?"

Alan: "When you say, when you want."

They agree Catherine will come back in two months time and they'll see how she got on. Catherine leaves the room. Alan turns to me: "It is important in this age group not to be judgemental, and to try and create the image 'who is looking after them?' And there is only one person who can and it's them." Alan points to the chair Catherine just left.

One hour later in the after-clinic team meeting, the former consultation becomes:

Alan: [*picks up a brown file*] "Catherine...Catherine is fine, doing very well, lively, bubbly. Catherine likes Walkers Cheese and Onion crisps, so I think she's got very good taste."

John: "But, did you notice, she has these absent eyebrows?"

Alan: "What do you mean 'absent eyebrows'?"

John: "They're not there."

Madge: "Are you sure, she didn't just wax them?"

John: "No no, and no, she's got loads of hair." [*turns to Adam*] "Do you know anything about that, any studies?"

Adam: "About what?"

John: "About" [*turns head back and thinks, John loves acronyms*] "AES, Absent Eyebrow Syndrome with diabetes."

[*laughter*]

The first time I attend this health carers team meeting I experience it from the perspective of a patient. All my previous visits to hospitals were as a patient, facing what I perceived as a community of nurses and consultants, who stayed when I left. Now, I find myself on the other side. All patients are gone and I am still here. I sit with the doctors as they are discussing their patients. My first reaction is that I shouldn't be here. I am not a health carer and they will discuss private information on patients. What I think will be just a formality, a sharing of medical information, turns out to be full entertainment. I am disturbed by how the young people I just saw in clinic are now joked about with a big sweep of the broom: "an absolute nightmare", "quiet as ever", "doesn't seem very happy", "can't figure her out". They are reduced to three words. That is how the doctor they'll see in three months might remember them, from the epithet assigned by his colleagues. I mind the health carers picking up a file from the pile, opening it, saying a patient's name, judging the person with a few words or some exchanged sentences, banter flying around, closing the file, dropping it next to the chair, and going to the next file, next patient, next joke.

The joking I mind is, though, very functional. Being personal about a patient and including his/her life is beneficial as it is crucial to know patients' background and family situation, mainly since in Millness, for some patients, as one nurse says "diabetes is the least of their worries". Though this could also be done in a more neutral way. The joking makes this late evening discussion, where everyone is tired, lively and fun, engaging the whole team. The consultants and nurses establish their positions. The female staff, both nurses and consultants, are more careful and concerned in their comments, they will always express their concern or disapprove of too harsh jokes by the male consultants. The team, which only meets once every month, is partly built by this lively half hour. With these funny personal stories I remember much better what is said about whom, and I will remember them next time they are discussed. Oh yes, he is the one who plays golf, he's the banana, she's the girl with the Absent Eyebrow Syndrome. If all patients were discussed as I expected: "John, his HbA1c is 8, he is doing fine", no one would stick in my mind. The way the consultants talk about their patients makes them stand out. By the third clinic, I find some jokes funny, yet I notice this does not make me care less about the patients. I do not disrespect them. In a way, I

am more involved with them, by hearing good-humoured jokes about them; they are more a person to me. I am more engaged with them now than if talk would only be about their HbA1c levels and micro-albumen.

2. The Paediatric Team and Clinic

2.1 Different From the Adult Team

The Young Adult clinic has a very high DNA (Did Not Attend) rate.[5] While the adult team explains this by "they are teenagers, they don't want to be confronted with their diabetes", the paediatric team instead puts the onus on the health carers: "young people do not like the clinic, because it does not offer them what they need".

While 'young adults' are located with the adult team, it is striking how the paediatric team has strong ideas on adolescents with diabetes. Two elements are at play here, personal involvement and professional orientation. The paediatric nurses and doctors have developed personal relations with the youngsters under their care. The three nurses of the team, Marion, Sally and Catherine, aim at named caseloads: every nurse has her fixed patients, whom she visits at home and actively follows up. The nurses have known 'Johnny' since he was a baby until he decided to go to college, with all the hiccups along the way. When the moment has come for 'Johnny' to move on to the Young Adult clinic, they have difficulty seeing him go. Not only because they care for him but mainly because the paediatric team's approach to treating young people with diabetes stands diametrically against the adult team's approach. In fact when asked about their thoughts about adolescents with diabetes, the paediatric nurses use the Young Adult clinic and the adult team's approach as the benchmark in contrast to which they define themselves. 'We are/do what the adult team is/does not'. I take this definition of themselves in contrast to the adult team as the most poignant sketch of the paediatric team's approach towards young people with diabetes.

[5] Never having questioned the term, I am not sure whether this is a health carers' joke or a usual term.

The paediatric nurses 'know' that young people do not like the Young Adult clinic. Some young people are reluctant to leave the Paediatric clinic and when they have to, they might stop going to clinic altogether. The nurses understand, as they do not like the Young Adult clinic themselves. Both sides stress the cold atmosphere and the doctors 'checking up on patients'. From giraffes on the meter and magic cream, to full vein blood taking, white coats and berating if blood results are not good. Welcome to the real world.

Paediatric nurse Sally classifies the Young Adult clinic as "very persuasive, prescriptive and pressuring". She understands why young people do not want to go to the clinic, she wouldn't go herself (she has diabetes):

> "The teenagers hate the Young Adult clinic. They say that the atmosphere is different; it's like a doctor's waiting room. It might be because they are nervous, some of the mums tell me their kids are nervous when going to the clinic. They are worried that the only interest of the doctor will be in their HbA1c and they feel they will be told off. The adult physicians follow the medical model of health, they look at the HbA1c, whereas John (head of the paediatric team) uses the paediatric model of health, even in the Young Adult clinic. That is why young people in the Young Adult clinic ask to see John, because they like him and his approach. There is a top-down approach at the clinic and young people feel their voice is not heard. They prefer the holistic approach."

Paediatric nurse Marion summarizes the difference between the two clinics as follows: "Young people (paediatric) carers look for a solution, instead of: this is how it is and you'll just have to deal with it."

2.2 The Discourse: Young People and Diabetes

The paediatric nurses state that the Young Adult clinic does not offer young people what they need. They do know what young people need. How come?
Dr. John, head of the paediatric team has a long-standing interest in the adolescent age group and pilots a specific approach in paediatric diabetes, with which all team

members, nurses, doctors, psychologist and dietician, agree, while adding their own variations. This shared interest led to an anthropological study conducted with the team and adolescent patients, which had a huge impact.[6] All team members are aware of, and often refer to, its findings, like for example Catherine: "We think adolescents are just being stupid doing the wrong things, but this is not how they see it. They are actually, how did she call it [*Catherine pauses and tries to recall the correct term of the report*] I forgot the word, they are doing something like 'pragmatic decision making', they are testing and trying out, and we should look at it like that that's what they are doing." Based on the study a discussion evolved on the issue of how to best treat adolescents, this 'most difficult group' of the diabetes population. When I talk to each of the nurses, Sally, Marion and Catherine on their ideas on adolescents with diabetes, this is clearly not an unfamiliar topic to them, rather one on which they hold strong ideas:

Nurse Catherine:	"Adolescents are difficult."
Griet:	"You mean difficult people or difficult to treat?"
Catherine:	"Difficult to treat. There are so many problems."
Griet:	"Why are adolescents difficult to treat?"
Catherine:	"Because, children, you can tell them what to do and they do what they are told. Whereas adolescents will say: this is not what I want to do. And it's difficult because it is about telling them what to do. But we have to find out: what would suit you?"

All three nurses base their knowledge on adolescents on their own experience: "I know what it's like to be a teenager. You don't do what they tell you to do", "I know what it's like in the house, with teenagers." It seems that in being an adolescent with diabetes, the problem of adolescence comes first, diabetes adds an extra difficulty. Or to quote Catherine: " Diabetes is very straightforward, but it gets very complicated by... [*she hesitates, I suggest 'life?'*] Yes, all the social stuff."

Marion: "Adolescents need to be dealt with specially, they need a lot of support. (...) They want to do things on their own, away from their parents, but they need as much support as before or even more. They need to be kept in focus; it is very

[6] The PhD research by Alex Greene (2000) as mentioned in the Introduction.

easy at that age to feel invincible. They have a lot of choices to make: job, university. They need someone they can relate to, they should be able to drop in, without an appointment. They need to have someone specific treating them, they like to have one person to build a relationship."

Where are the parents? All this sounds like psychological, caring support. When we talk about this relationship between health carer and adolescents, which is crucial to the nurses, I keep throwing in the token parents, as to me this relationship sounds like a parent-teenager relationship. I continue to be amazed and try to get a precise understanding of where exactly the parents are, according to the health carers, in teenagers struggling with diabetes.

Marion: "They don't really get support from their parents, school or even the Benefit Agency.[7] Parents want to shift it all over to the adolescent, they feel they have done enough and now it's the adolescent's responsibility. (...) Parents still worry, I think there is almost no case where the parents completely don't care, but they don't want to do the work any more."

Sally: "At their age it is their diabetes, many of them come without their parents."

Griet: "Is it their diabetes because they want it, or because the parents say: O.K., you're old enough now, now it's your responsibility? How quickly is there this need for young people to be independent?"

Sally: "Of course it is not linked to an age and we don't say: right, now you're 14, now you have to take care of your diabetes. But young people grow from dependence on their parents/family to independence. Of course parents worry all the time, but maybe it's a bit that they hand over, or that the young person feels she/he needs to be independent. (...) Young people don't want to talk about diabetes with their parents because they nag, they do want to talk to health carers but mainly they would need to talk about diabetes among their peers."

[7] Marion relates how the Child Support Agency (financial support) wrote a letter on the case of a girl of 12, saying she shouldn't be getting help from her mother any more since she is now 12 and she should be able to do this herself.

Sally mentions how two years ago she ran talk-groups for teenagers, together with the team psychologist. The team found out that what they thought teenagers wanted was totally different from what they actually wanted. The groups were a mixed success: "Girls are more open, more ready to talk about it, boys, Scottish culture [*Sally sighs*] don't open up."

The nurses have painted me the following image: teenagers have the need of a relationship of trust and care with their health carer, a relationship from which they can get support and self-esteem. They do not really have this relationship with their parents in most cases, because when you are a teenager, you tend to feel that parents nag, so you don't want to talk to them. Also parents tend to hand over the diabetes management to their teenagers, as it is time for them to grow independent and take care of it themselves, with the help from the health carer. Apart from not helping, parents often make the situation worse: Marion tells me how shocked she was during the first 6 months of her job, when she did many home visits. "It seemed everybody was separated, what was going on in people's homes? There were even two cases where the families completely ignored the diabetes and the children would end up in hospital with DKA (diabetic keto-acidosis: a dangerous condition caused by very high blood sugar levels)." Catherine adds: "But of course you don't say to Mum, the diabetes control is bad because you and your partner are falling out."

Yet so far all talk has been on support and care, no mention of medical treatments or physiology. I am puzzled. After all I am in a diabetes clinic, asking medical staff about the treatment for young diabetic people. Imagining myself as one of their patients I would feel they are getting too personal, I am there for my diabetes, not to do something about my (lack of) self-respect. All these things sound like what your family and mainly your parents give you: a chance to talk, a listening ear, trust, and self-esteem. By hearing them talk like this I forget I am in a hospital: more like a psychological counselling session.

I resolve to specifically ask about the diabetes side of things, and thus maybe will hear more about the medical treatment. Since the team starts from the adolescents' perspective, I attempt to broach the subject by asking what the nurses think is the adolescents' main worry about diabetes.

Sally: "Young people are embarrassed of being seen to be different. They are not ashamed of having diabetes, they just don't want to be confronted with it, that is why many give injections in the loo, because otherwise people ask questions and you have to explain and you are reminded of your diabetes. The fact that they need to have a routine is very difficult, as a young person likes to smoke, likes to take drugs, even if I am so against taking drugs, likes to go out, sleep late, they have this risk-taking behaviour. They don't want to take their long-acting insulin, so they won't do it."

Do they worry about having diabetes, a chronic illness?

Sally: " No, they are quite blasé about it, they don't realize the risk. They know it, but they don't like to think it will happen to them. (...) Later they'll tell us: why didn't you tell me? And we did tell them. But if they don't do as we asked, advised..."

I am surprised at their use of the term 'asked', 'advised'. They don't *tell* them what to do?

Sally: "If you talk to the adult diabetes nurses, they'll tell you what we do is 'mamby-pamby' young people [*we agree this means pampering*], that we don't scare them enough. But, if you show them pictures and scare them, you don't give them much."

Marion: "It is important to be honest with them and say: if you do this, this is what will happen. It is sometimes frustrating, like with kids that don't take their insulin, and you know they are not taking their insulin and you are asking them to tell you that they don't take it, but they don't, they keep saying that they do take it, then you can only be sympathetic to them. Adolescents, you need to give them a face saving way out. They'll say: of course I am taking my insulin. We say: what can we, the team *and* the young person, do about it? If the situation gets very serious then we'll say: you can't keep doing this, something has to change. Sometimes then a paediatrician will get angry, though they are very laid back most of the times, but then they'll say: hang on, this can't go on. If they give a bit of a grilling, we always make sure there is a nurse present, so she can go after the patient and say: you know, we say this... and console and comfort."

The difference then, between centres, seems to lie in *when* 'the situation gets very serious', and when there is the felt need for the paediatrician to interfere and get angry. As long as the situation does not get serious, the main aim from the Millness team during adolescence is "to keep them on board and as healthy as possible".

Dr. Caroline summarizes her approach to adolescents thus:

> "You just pray they get away with adolescence and come out of it without too many problems. The main aim is to keep them coming. See that they are growing, that they don't have a too high HbA1c level, lower than 10 is good, and support them through problems. Because some of them: their lives, their parents' situation is very difficult and chaotic. We can't solve everything, we can't bring their parents back together, but we can give the kids support. If it gets to a stage where we are really worried, then we have to do something more drastic. But for the majority the main focus is just keep them on board."

The nurses often stress they have to be realistic in treating adolescents, not expecting too high goals.

Sally: "So when they come to us and ask advice about what to do when they take drugs or alcohol, as much as I am against drugs, I say, I appreciate you being so honest and open about it, this is what happens in your body when using drugs so this is what you need to do about insulin."

I wonder whether parents are not angry about health carers giving advice on unhealthy behaviour?

Sally replies that indeed they are, but she explains that you have to be realistic, "you can't stop young people drinking or, taking drugs, as this is what young people do. So we prevent further complications and acknowledge the reality. Health carers need to look at what young people do, instead of looking at them through pink glasses, wishing the situation were different."

Sally would like to make the Paediatric centre holistic. In the Young Adult clinic with its top down approach, the young people feel their voice is not heard.

Griet: "Do they want to be heard, do they have this need?"

Sally: "Oh yes, they want to be heard, to be empowered."

Griet: "This is a complicated term, since it also means responsibility, do they want that, or just to be heard and not really take the consequences?"

Sally: "Good question, ok, maybe 'pro-active' is a better term."

Sally: "In the talk group with the adolescents it turned out that what they wanted was the opposite of what the team thought they wanted."

Griet: "And is that what you gear the care towards? Find out what they want and offer that?"

Sally: "Yes."

Griet: "And not start from: this is what we offer them?"

Sally: "No."

Sally: "If we show the young people they can trust us, and we care for them, then they'll trust us and respect us, if we respect them."

Griet: "So all the effort is on the health carer's part?"

Sally: "Yes."

I refer to children being independent at 14 and parents handing over their diabetes management, if not to the teenager then to the health carer, and ask about this attitude that people seem to expect the state to help them, instead of taking their own responsibility. Sally agrees there definitely is some of that. When I ask Marion the same question about relying on the council and the state, she replies: "There seems to be this dependence here on health services to put things right when they go wrong. But from the start of the NHS that was their slogan: "from the cradle to the grave, we'll take care of you".

My conversations with the paediatric diabetes nurses leave me with the following E-fit of adolescents with diabetes: adolescents 'as if', a constructed reality. Adolescents with diabetes in Millness:

- *Are difficult (to treat)*
- *Need a lot of support*
- *Do not want to be/do different from their peers*
- *Do not realize the risk of diabetes: 'it won't happen to me'*
- *Do not want to be told what to do*
- *Do not want to talk to their parents, because they nag*

So far, I have sketched the discourse on young people with diabetes in Millness, now we look at how care for young people is 'done'.

2.3 The Practice: Clinic Consultations

The clinic consultations follow a certain scenario, based on the appropriate approach to care for adolescents. To illustrate, I show how nurse Sally conducts her clinic consultations. Sally's style is similar to her colleagues', though she is particularly caring and encouraging with her patients. As the youngest nurse (36) and diabetic herself, she is quite popular with some young people: "I think they identify. I want to show that life is for living and that even though you've got diabetes you can do many things."[8] I would suggest that not only do young people identify with her, she definitely identifies with them.

The following two consultations, during one afternoon at the Paediatric clinic, show how Sally's main concern, consistent with her affirmations before, is with the young people's psychosocial well-being. Most conversation borders on how they feel and cope with those problems, problems of being a teenager, and on top of that, having diabetes. The medical diabetes treatment comes second, and will be adjusted to better fit the young people's daily life and activities. Sally makes clear she cares about the young people, she repeatedly tells them so. She gives them support, though importantly, not in a patronizing way, she often stresses she does not want to nag. She does not tell them what to do, rather she suggests, she negotiates, and what she suggests is what she thinks the young person wants to hear. She gives them a face saving way out. The way she treats —the wrong term here, she *cares* for— the young people, fits perfectly the image of young people with diabetes sketched by her and her colleagues before. Sally's holistic approach in action. [In bold those sentences that specifically characterize her approach as sketched above.]

[8] Before becoming a paediatric nurse, Sally worked in a city council 'Health and Information' centre, a meeting place for adolescents on sexual health. Part of her job was to provide the morning-after pill and to advice on how to take the least risk when engaging in risk-taking behaviour. Parents complained of giving teenagers advice on irresponsible behaviour and the centre received some bad press.

Stan, 14, comes in the consultation room with his dad. He was diagnosed with diabetes four months ago. The first times he came to clinic he was cheerful and chatty, coping surprisingly well, today it seems things have turned. He looks very pale, feels low, doesn't talk. His dad is worried that he is eating so much but is not putting on any weight. Stan is weighed and he has lost three kilos in four weeks. Sally asks how he feels and discusses his insulin doses with him and his dad.

Sally: "What is happening is, and this is where it gets really complicated, you're probably eating and eating and the insulin we give you is not covering it; so the amount of insulin, we have to look at that, I think we'll have to increase all the doses. [*She takes the diary where he writes his daily blood test results and writes 'if there are moderate to large ketones (substances produced by the body as it breaks down fats or energy) and blood sugars are over 17, then contact the diabetes team'*] then you need more insulin.[9] This doesn't mean that we will put you into hospital Stan, just, you don't look well at all, it must feel like you're trudging through treacle, your legs are probably aching. It sounds quite complex; I hope I am making that clear. **I hope I am not patronizing** either. The other things, which may be a possibility, because you are on 3 injections a day, we might put you on 2 injections, sometimes people have better control on 3 injections, sometimes better on 2, **you have been great from the start Stan**, looking at your weight and at the amount of insulin, we need to juggle it.[10] What do you think? Do you think it would be easier to give yourself 2 or 3 injections a day?"

Stan does not know.

Sally: "Again, this is something I was expecting, 'cause at the start you were 'yes, no problem', but after 4 months, you cannot have a break from it, it becomes a hassle.... **Don't be so hard on yourself, you're doing great**. The fact that you've done 3 blood tests a day is fantastic, go down to 2 a day."

Stan and Dad leave. Sally turns to me and says it might seem to me she is contradicting herself all the time. Like with Stan, suggesting to go from 3 to 2 injections, whereas the normal procedure is to move up, so from 2 to 3 or at least stay at 3 when on it. I admit to

---

[9] High levels of ketones may cause nausea and vomiting, fast breathing; in severe cases, it may lead to coma or death.

[10] For clarity, I write the number of injections and blood sugar tests in number format.

her I was a bit puzzled. She explains that she knew he was not taking his 'Rapid' (insulin type for late night injection) insulin. She saw it from his test results and also "he had his head lowered and thought 'don't ask me if I am taking my 'Rapid'. So, instead of making him say he didn't take it anyway, I suggested to him we would cancel it. **Sometimes you say what they want to hear and what they won't tell you.**[11] Since he wasn't taking it, it would be better to deal with the situation as it is." I suggest that she didn't ask Stan, or mention the possibility, of him not taking his insulin? Sally replies she didn't want to mention it with his dad there, who seemed so 'overpowering'.

By saying what they want to hear, like suggesting them a regime which would suit them better according to their lifestyle, and since they are not following the one they are on, Sally suggests an easier one. This fits in her strong conviction that health carers have to deal with the 'reality'. Things are the way they are, and we have to take them like that and start from there, work with that and see: how can we make it easier for them, better? And Sally, having diabetes herself and still being young, thus feeling close to teenagers, knows the reality and knows what it's like, and this is very important. She knows how it feels to have high blood sugars (like being on a roller coaster, the worst feeling), she knows what teenagers are like, she knows they sleep in at the weekends, that they do drugs, drink etc..

To follow a consultation with Sally is an exercise in reading between the lines. When she says: 'you are doing great, don't be so hard on yourself', it usually means you are not doing well, it should be better. —This may sound harsh from me, but I try to understand it as Sally wanting to encourage people when it is tough. Another clue is that when she asks what I before would take as genuine questions, she is actually checking a suspicion. She tries to show the young people that she knows what they are up to, that she does not judge them, but that she cares.

With this feedback, the former consultation and Sally's insistence on Stan going back to 2 injections made a lot more sense. I am now more aware of Sally's practices and am thus warned when a similar thing happens during a following consultation.

---

[11] Interestingly, this seems to happen on both sides. Nurse Sheila said about Britney, a girl who was unhappy about her insulin pump (another type of insulin therapy, the protagonist in Part Two of this dissertation) but did not want to say so: "She does not lie, she just tells you what you want to hear. She wants to please people." Thus Sheila, suspecting Britney was not using her pump correctly and wanted to

Sally suspects that her next patient, Alison, is also skipping insulin injections to lose weight or just because she cannot be bothered to inject. Alison, 15, a trendy looking girl, was diagnosed two years ago, when her parents split up, which according to Sally had a big effect on her diabetes. Today Alison comes in with her mum. She is tired and not well. She is currently on a regimen of 4 injections a day. Her blood sugar result is high. Sally tackles it her way.

Sally: "Are you happy on the 4 times a day, would 3 injections as opposed to 4 be easier for you? I'll see what (doctor) John says. Your HbA1c, 11, is too high, and you know that yourself. Do you feel physically unwell?"

Alison: "I feel very tired."

Sally: " You look exhausted."

Sally: "With young people, and I know this for myself too, you get up in the middle of the day, and think: I haven't given my breakfast insulin. It's entirely up to you Alison. **Young people have chaotic lives, that's part of being a young person**, and if you give your breakfast insulin at lunchtime, or you miss out on it. It sounds very complicated, it is very complicated. **Young people live chaotic lives, that's how it is**, so we try and tailor regimes for your lifestyle. The regime you are now on, you have no leeway, the one I am suggesting gives a bit more leeway."

Mum: "Saturday and Sunday she has a lie-in, it is 10.30 when she takes her first injection."

Sally: "That's still late Alison."

Mum: "Then she moves the lunch time injection."

Sally: "That explains your high blood sugars when you go to bed."

Mum asks how they then should do it differently to get it better.

Sally: "You can stay in bed till 10.30 but no later. **Oh, I'm cruel**. Alison, you've done really well, it's a very difficult age to get diabetes, **you want to do what your friends do**."

Mum: "She's been very good, but she enjoys when friends are around to chat and sleep later. There are harder things to get over, she'll just get over it."

Sally turns to me: "**This girl is going to be rich and famous.**"

---

quit, told her: 'I think you should go off the pump'. "You should have seen her face, like a huge weight lifted off her shoulders."

Griet: "An artist?"

Sally: "Yeah, anything, or catwalk, see how tall she is, with her entourage following."

Mum: "What about mentally? She said to be … she felt really fed up, her environment wasn't stimulating her, friends, school. I was happy she could talk to the psychologist. There's no stigma attached to it, though you might not want friends to know."

Sally: "Diabetes is not easy, it does not go away. Psychologists, I see them as buffers, sometimes you feel so low, whiney. I think you're dealing with it very well Alison, and a lot has happened in your life recently. What I'll do, I'll see you again, **I'll never give you a lecture, I'm with you 100% Alison.** I think there's a lot to be angry about when you have diabetes: high sugars make you feel lousy, diabetes makes you moody, also you have an erratic lifestyle now and you are having exams etc.."

Alison:"I feel quite bad, 'cause I've been bad to mum and dad and they've done nothing at all, or I feel like crying and I don't know why."

Sally: "Again, **I think that's normal teenage behaviour, being horrible to Mum and Dad.**"

Alison and Mum leave the room, Sally turns to me. "This is a real problem, Alison obviously does not take her insulin at the weekend. That's a real problem. At the Young Adult clinic, no disrespect, the doctors say 'HbA1c is so much, so, we give more insulin'". Whereas Sally would introduce insulin type 'Actrapid' for the weekend only, instead of increasing the whole dose of insulin, since the dose is sufficient, when she *does* take it in the week. Sally explains: "Actrapid gets the blood sugars down, whereas if she gives the whole dose of insulin at lunchtime and then the whole dose at 2 in morning**, and this is what they do at the weekends,** her blood sugars are gonna be very low and she'll feel lousy." Sally again takes into account the reality of the situation. She looks for the specific, contextual reason why the results are high: not because the dose is too low, but because at some moments insulin is not taken, and this is what teenagers do, that is their lifestyle.

A big reason why Sally is so understanding and accepting of reality is that she identifies with these young people: she has been there herself, she knows how they feel, how difficult and frustrating it is to have diabetes and live a teenage life. She cares

about them. But does she take care of them? She accepts reality as is, she definitely confirms it, confirms the behaviour of teenagers 'that's what teenagers do'. Or does she construct it?

Throughout the consultations she profiles herself as a carer, mentor, almost a life coach. She gets personal: understanding the young people, giving them compliments, saying how pretty or bright they are, the great future ahead of them. Personal, though —maybe precisely because of that?— it does not seem genuine. One afternoon of consultations gives seven similar scenarios with standard phrases. Then there is the striking discrepancy between what she tells the young people in the consultation, and her comments afterwards. During consultation the emphasis lies on the psychosocial, the medical talk is almost absent. Once the young person and parent have left however, the medical 'facts' are what is sighed about, and what remains in the file notes.

All in all, I feel these consultations are not very engaging. Not engaging the young people in their diabetes routine and hands-on management, nor it seems, in their personal problems. The young people realize this too. Though all like Sally, many will say they hate going to clinic as it is boring and always the same 'oh you look well' talk, they only go because their mum makes them, and for the blood test, which monitors the evolution of their sugar levels.

The approach to adolescents diabetes care by the Millness Paediatric team is quite specific. But there are many other different ways of *doing (adolescents with) diabetes*. I will concretely describe one such very different way, the way of a centre in Belgium that gets 'perfect' —'too good to be true' Millness health carers say— results with adolescents.

But first, after so much talk about adolescents, let us meet them and see what they say.

***

2

Millness Young People

In the clinic I meet the consultants and other health carers as agents, performing their professional role. It is where I meet them as significant partners in the diabetes relation. Yet, it is not the appropriate place to meet the young people as conscious agents in their relation with diabetes. The clinic visit, two hours every three months, forms a microscopic part of their diabetes lives. Not only in time, but also in practice. The weight, height, finger prick test and ten minute chat with the consultant is not their diabetes, more likely just a detail. In order to get a richer view of diabetes-as-lived, I have to visit the young people at home. Where they live their lives with family and friends, with space for interplay of several selves. Out of the hospital setting I can see Lisa, Gavin, Ewan and many others as more than merely diabetes patients.

We have heard how the paediatric team thinks about adolescents, how they are, what diabetes means to them what they need and thus how they should be approached. We have then seen how consultations go and how the health carers talk to the adolescents. Let us now consider what the adolescents themselves say about having diabetes, what they mind about it, what they worry about and how they deal with it; What do they think of the clinic consultations and how would they prefer them to be?

A lot of thinking and struggling has anticipated this section. How to put 20 interviews with 20 different young people into one piece of text? The classic formulas of grouping by theme and then gather different opinions on the one topic spring to mind. However, that would be a poor rendition of colourful data. My solution here is to sketch three young people (Gavin, Ewan and Lisa) and their story on diabetes. I want to show them, with their mum joining in the conversation, with their family situation. Most of all I want to steer clear of breaking up a conversation to switch to another quotation from

another person, when the only thing linking them is that they are in the same age group, have diabetes and visit the same clinic.[1] I do not want to present a case study saying: 'Most teenagers mind most about diabetes that…'. I am too conscious of the fact that they are all different and that what they say about one issue is linked to what they think about another. Furthermore, the last thing I want is to say what teenagers are *really* like and how they *really* think about diabetes. For this would be just another version of the previous chapter and me doing the same thing as the health carers. So how can we talk about them? And is there even a 'them'? The only group there in this case —and I don't see it as a group— is the people I happened to talk to, about the same illness that affects them. That is all.

Yes, there are answers and themes that keep coming back. What is the value of grouping these? To give a general image? Probably. However, everything I say I want to surround with disclaimers, 'she says this but of course not all think this, this is probably linked to her….'. I do not want to say 'this is what teenagers think about diabetes'. What do I want to say? I want to show Ewan and his struggles and worries, I want to show how Gavin lives his life with it, I want to show what Ewan's mum thought about the clinic consultation and how she was treated. I want to show just a rich and varied tableau, a bit like a Breughel painting indeed, where you see all different people doing different things, a picture which could then be titled: teenage diabetes in Millness, 2002. The spectator can get impressions by studying the canvas, observing what people are doing, and wonder or think about certain postures, tools or interaction between people. Thus here I talk about Gavin, Ewan and Lisa. [Certain phrases of the dialogues are in bold: relevant phrases illustrating points I will come tack to in the discussion of this data.]

I start with Gavin. First with a consultation in the clinic, where I met him for the first time, and then the chat I had with him two weeks later, in a coffee bar. Two different Gavins, but one more flesh and bones than the other. I intend this as an illustration of another reason why the clinic is not the appropriate place to get to know young people (and their relation with diabetes): at consultations, most young people **do not engage**. They do not feel connected to the clinic, the health carers nor the other young patients. Though the health carers 'try to engage' the young people, enquiring

[1] Though this is how they are constructed and, I argue, what they (predominantly) *are* to the Millness health carers.

about school and future plans these are mostly polite enquiries in between the questions about insulin dose and diet. The young people do not engage in their answers, they are here for the routine check, not to talk about their personal lives. [2] As we saw with Catherine's visit to the clinic (in the previous chapter), she came, was seen, and went. She does not feel the need to engage. She feels OK and if the doctor says she is doing fine, that's fine. In consultations we only see a small part of the young people, playing the role they are there for: the patient.

1. Gavin (15)

The Paediatric diabetes clinic, Millness Hospital, Monday afternoon. I am sitting in clinical consultation room 2 with Dr. Veronica. Gavin comes in with his dad. Dad sits throughout almost the whole consultation with arms folded, silently; he does not look involved or interested. This conversation has nothing to do with him. Gavin, crew cut, big piercing in his nose, is flushed, mumbles answers when he has to. He seems nervous. I don't know if this is him or whether today he is intimidated by young Dr. Veronica, who is wearing a skirt and a tight sleeveless shirt. Veronica is new in the team and Gavin has never met her, or me, before.

Veronica: "Hi Gavin, how are you getting on?"
Gavin: "Fine."
Veronica: "Do you have any problems?"
Gavin: "No."
Veronica: "Your HbA1c is very high. What can we do about it?"
Gavin: "I haven't really been in for my tea the last three weeks."
Veronica: "Why's that?"
Gavin: "I've been at the studio."
Veronica: "Is that an art studio?"

[2] There are of course exceptions, like Rachel who found out she was pregnant and asked for advice. She had a long chat with a (female) paediatrician and nurse and they gave her all possible support. Or Kylie who is on drugs, she gets a longer consultation than others, and the nurse often visits her at home. While Kylie does not engage in the consultation she barely answers when asked a question and stares in space (she is on tomazepam and diazepam, E's etc), she does come to the clinic every three months, so for her this might be a big engagement, and an effort to see some caring adults.

Gavin: "No it's music, I play in a band."

Veronica: "Which instrument?"

Gavin: "Guitar."

Veronica: "So what does it mean that you are at the studio?"

Gavin: "I've been giving my insulin at 6 instead of at 5. I give it at a friend's house."

Veronica: "Are you keeping an eye on your blood sugars?"

Gavin: "No."

Veronica: "Do you do blood tests?"

Gavin: "No."

Veronica: "The problem is, today I don't want to increase your insulin, because we don't really know what you need since you haven't been taking insulin or testing properly. So why don't you monitor over the next week and I'll ask the nurse if she gives you a shout? Which one do you know best?"

Gavin: "No-one."

Veronica: "Do you do any exercise?"

Gavin: "I go skating every night."

Veronica: "What about food?"

Gavin: "I don't eat during the day, only in the morning, breakfast and then at 6. For lunch I'll just have a packet of crisps."

Dad explains: "In summer, it is difficult finding a pattern, but with school there'll be the usual meals again."

Veronica: "I wonder if it would be worth trying to have a more normal lunch like a sandwich."

They discuss other food possibilities for Gavin but neither he nor Dad seems very interested. Veronica says she will ask nurse Sally to contact him after a week or so and they can then go over his tests. Gavin and Dad leave. Veronica dictates the letter to Gavin's GP on tape: "Gavin's lifestyle is very erratic at the moment".

One week later

Gavin fits the 'stereotype' the health carers have in mind when they speak about adolescents. Gavin's sugar levels are very high, even according to this clinic's standards, though he calls his control level good, and is not aware of any problem. As

the consultation was very short and Gavin was not very communicative, also, his life did indeed seem a bit erratic since he is never in for his tea [*where is he all evening and does he eat, this 15-year-old boy?*], I asked whether he would mind to have a chat sometime about life with diabetes? Fine. Gavin suggests a coffee bar in a busy shopping mall in Millness. He arrives with his skateboard that during our conversation he will balance between his knee and the table. He looks like a skater, half-length trousers, and trainers. He talks softly and quickly, in half sentences. After half an hour his mobile rings, his girlfriend Sophie asking where he is. 'I'm still here, call me back in 15 minutes?' We talk ten more minutes and he goes. [My questions between — —.]

Gavin has had diabetes for five years, got diagnosed when he was 10. He does not think about it much. "I didn't know what it was, I was shocked, because I knew it was a big thing." —Why?— "Because it was a big word, diabetes. It meant I had to take needles and I didn't like them and I knew I had to watch me diet, not eat too many sweets, no sugar." —Who told you all this?— "My brother, he's eight years older than me." —Does he have diabetes?— "No, but he knew about it and told me what to do." **—What about your parents?— "I don't speak to my mum or dad." —Why not?— "I just have nothing to say to them, I can't talk to them**." Gavin was close to his brother and spoke to him, but he has moved out now. When Gavin now has a problem he'll speak to his friends, not his parents. I mention how his dad was with him at the clinic. "Normally my mum comes with me, but she had to go to a doctor's appointment with my brother." —Do you like her to come with you?— **" I ask her to come, it's reassuring."** —Does she help you with your diabetes?— "**My parents tell me what not to eat, and I do it.**" —Why?— "**Because I don't like confrontation.**" —Are they worried about you?— "Yes, **sometimes they are too worried.**" —What about your friends, do they treat you differently?— "All my friends know I have diabetes, my best friend Russel, he does not treat me differently. Yes, if they offer me food, they'll ask: can you eat this?" —Do you feel different?— "Like sweets, when they're eating them I might want some but I don't take them." —Why? — " Because my blood sugar is high, I feel horrible then." —What is the main thing you mind about having diabetes?— "The injections, always to remember to take it because the evening one I have at a friend's house, so I take them with me."

Gavin does not take his injections in public, where there are a lot of people. Once he did it in a restaurant and everyone was watching him and even afterwards they

kept looking at him. He does not mind that people know he has diabetes, he just minds the fact that people were rude, staring at him the whole time, he does not like people looking. "In the first year at school, people used to make fun of me, they were making jokes, calling me 'druggie'." The best thing about not having diabetes any more would be not having to take the 2 injections at the time of food. He explains that when the time you eat and you take injection is linked, then you have to make sure you eat at fixed times, this is difficult. [*I remember the 'erratic' lifestyle of the consultation.*] Gavin sometimes worries about diabetes in case something happens, e.g. either that he has too much sugar or has a hypo. They told him about complications and what might happen later if he had bad control, but he says he did not take it into account then. "Now I am worried in case it happened. Like the nurse told about eyes and I don't want to get bad eyesight. I'm 15 and now I would like to know, I think, I'd watch out, if I knew." Diabetes is not a problem to him now and it is kept under control. — Who controls your diabetes?— "Me. And my mum, cause she tells me what to do." — How? — " She phones me every evening to ask if I took my injection, because I am at a friend's house." — Do you mind she calls? — " No, I don't mind."

Gavin visits the Paediatric clinic every three months, though sometimes he does not feel like going, like he had to go on his birthday. —Why do you go every three months, is it helpful?— "I can see the blood test part helping." —What about the consultation with the doctor?— "I don't like it because they speak down to me." — All of them?— " No, Dr. Scot, I don't like him. **He is patronizing**. He doesn't talk to me, he talks to my mum and asks her the questions." —Do you think this might be because you don't want to talk? — "No, it's not, because once he asked about my dose and my mum wasn't sure and I told her and still he kept talking to her. And I don't like him anyway. I like Dr. Caroline." —Why?— "Because she speaks to me and she asks how are you. John starts with 'your HbA1c is too high'. I like it when they know me or ask how I am." Gavin would prefer to see and have one doctor and know before that he was going to see that person. Now he sits in the waiting room and does not know who he'll be called in by.

I ask Gavin if he is upset about having diabetes? "I used to be, for a few years, I didn't like me." — Why? — "'Cause I had diabetes." —What about it you did not like?— "'Cause I used to go low. I used to go low on stage, and I play lead guitar and I felt it coming." —So what did you do?— "I kept going, I had three more solos to play and I use to play on my knees and it was really difficult to keep going. And after that I

needed to sing and my singing really deteriorated. So at the next gig I took some Lucozade before and I went really high. And normally before we start we make jokes about the audience and that time I was really hyper and the band could tell cause I really went too far. When I got diabetes I used to wonder who is me? Then after I was diagnosed I took up BMX (cycling) and that helped to take my mind off. I accept it now, I am fine and happy. Before and when I was getting diagnosed I used to get really angry, but in general, I am a cheerful person." — Has diabetes made you a different person?— "I am more careful. And sometimes I'd like to tell my friends why are you doing this? Like when they drink a lot." —Is it sometimes difficult like do you feel you can't do what your friends do, like e.g. drinking?— "I am sometimes more responsible than my friends. I don't feel left out 'cause not all my friends drink a lot, only two do, my closest friend does not drink at all." Gavin says he is never really tempted to do things he shouldn't. Like during summer holidays he was playing gigs all the time, only since school started again he has met his friends, and now he goes to the music studio every night. I ask him about this general idea that teenagers are risk takers and that they don't do what they are told to do. Gavin does not agree, he does take care. "Some of my friends are risk takers." —You?— "I have done a few stupid things and I do stupid things. In skating. Two weeks ago I got this piece of glass in my hand [*he holds up his hand*] and I've also hurt others, I skated over them but came down too soon." —You don't use kneecaps or a helmet?— "No. Some of my friends are wimps, they're afraid to … [*here he goes off into technical skateboarding terms and I am lost*]." Gavin thanks me for his hot chocolate and is off towards his friends who have called his mobile again.

Gavin, in his own words, 'does not speak to his parents, has nothing to say to them, can't talk to them'. Yet his mum calls to ask whether he took his injection, he asks her to come to clinic with him. His parents obviously are involved and concerned. Is Gavin mainly playing cool? Is he also playing cool about his diabetes? He has bad control, very high blood sugars. Yet he thinks (pretends?) that it is good, that he does not have to worry about bad eyesight. A few days ago in clinic Dr. Veronica told him clearly his HbA1c was very high and wondered what they could do about that. As this was the only message she wanted him to take home, she kept the consultation short and simple. Gavin explained his high HbA1c by saying he had been eating irregularly. Has he forgotten about this? Does he not want to do anything to better his control because this would mean more routine in his eating times, while he mentions that the best thing

about not having diabetes would be not having to have fixed meal times. Does he tell himself his control is fine and so he does not need to worry? Does he believe it?

2. Ewan (16)

The Paediatric diabetes clinic, Millness Hospital, Monday afternoon. Consultation room 3 with Dr. John. Ewan a shy, sinewy and pale boy, comes in with his mum. Mum, very involved in Ewan's diabetes, will almost guide the conversation, though Dr. John will try to gear the conversation towards Ewan, ignoring Mum at some points.

John: "Hi Ewan, How's school?"

Ewan: "Good."

John: "You're nearly 16?"

Mum: "How many days Ewan?"

Ewan: "25."

Mum: "He's counting the days."

John: "Still growing up then? How are your exams? Are you keen? Confident? Any problem with diabetes?"

Ewan: "Eating. I eat a lot."

Mum: "He's been misbehaving, to say last week that Ewan was depressed would be an understatement…"

John: "**Wait a moment, there is no such term as misbehaving, it is living with diabetes, which is difficult, and sometimes it goes up and down and it is about trying to find a balance.**"

Mum: "Yes, that's what I say, it's not about eating the right thing all the time…"

John: [*to Ewan*] "**Is diabetes stopping you from doing anything**?"

Ewan: "No."

John: "You feel happy?"

Ewan: "Yeah."

John: "You take your insulin OK? Your control is much the same as last time, quite high. As your doctor I would like to have it tighter."

Mum: "I feel guilty because when I go shopping I like to buy sweets all the time. So last time I went with Ewan and we were really strict and only bought healthy things.

But then I need some sweets in the house for when he has hypos and his brother Frazer eats a lot."

John: "Who is the worst in tempting?"

Mum: "Frazer"

John: "What are you gonna do?"

Ewan: "Art yeah."

Mum: "Ewan is academically gifted as well."

John: "I haven't got any simple thing for diet. When is it most difficult?"

Ewan: "Especially at home, cause I'm bored and I just go and eat to have something to do."

John: "So if the family really got together…"

Mum: "I tried for two years to lose a stone and a half and can't do it. I know how difficult it is."

John: "What if you had a family discussion and decide on it?"

Mum: "A few weeks ago we had for the first time a discussion in the house on drinking alcohol and Ewan is coming up 16 and he said he could start having a drink, whereas before he always said it was not for him. I'd rather he starts at home, but Ewan said he might start and I was horrified, I thought, how do I cope with that one? It is not so much the drinking but the drinking with diabetes."

John: "Ewan, you should also know there's a bit of a worry as far as diabetes is involved. To put it straightforward: the body gets rid of the alcohol by burning it off, it needs glucose to try that, a lot, so you burn up any glucose, so you have to watch it with alcohol. The classic scenario is: you have too much to drink; you go to bed and get a hypo."

Mum: "I'd think he'd go hyper because of all the extra sugar, but it doesn't work like that?"

John: "So, how are you going to sort this out? **It's this boring thing about diabetes again: you have to be sensible**."

Mum: "My worry is, if they go to discos they have a wee snort before they go."

John: "Adolescents and alcohol: we have to be careful, the way I try to soften it: Like now when somebody is driving, you don't drink, we all got used to this now, while 20 years ago that wasn't done."

Mum: "Yes, what I'm worried about is the combination alcohol-diabetes."

John: "Another group who don't drink very much: sportsmen, the concept of keeping healthy and fit for sports is cool now. If you could see this in relation to diabetes..."

John: "I think we carry on, we won't change anything in your dose, you said you had a discussion about alcohol.... At some stage in spring I think you can start coming to our Young Adult clinic, but first you'll come here a few times more."

One week later

I am at Ewan's house to talk to him about life with diabetes. Mum shows me into the living room and asks if she can join us, Ewan says he doesn't mind. Mum offers me tea and home-made banana loaf. As the conversation goes on and food and Ewan's struggles with food become the main topic, I grow so conscious of the piece of banana loaf in front of me, I cannot touch it. At the end I do because I do not wish to be impolite, but I only eat half of it and say I feel embarrassed eating it. Dad who has joined us halfway in the evening, says 'but isn't that the diabetic recipe?', I reply that still I feel uncomfortable eating. Ewan, Mum, Dad and I sit cosily in the living room, talking and drinking our tea, I feel like a psychologist. The talk is emotional for Ewan because he is struggling with control, food and diabetes at the moment, actually the last two years. He is often quiet, not being able to speak for the tears in his eyes. I feel for him, he is so hard on himself. Seeing this boy trying so hard and his mum and dad caring for him, I feel I am not doing much for them so I tell them how other people have the same problems... I still don't give them anything; I can't give them anything probably apart from my empathy and feelings.

When he was diagnosed with diabetes, at 10, Ewan did not know what it was. He was worried about whether he could still do football and running, when the nurse said he could still do sports, it was OK. When nurse Jane came to his house, and showed him a video, Ewan really found out what diabetes was. It meant he could not eat a lot of sweets, he had to test blood and do injections. While at the start doing blood tests was exciting, he would do them twice a day, now six years on, they have become a chore and he does them three times a week. They are what he now minds most about having diabetes, trying to do the blood tests and getting them done. He has become very relaxed about them and it is hard to go back. When he was younger he would just get on

with it, he had nothing else to do, schooldays were shorter. Now he is tired, has more to do, it doesn't fit in his busy schedule anymore.

I recall the clinic consultation last week and how he and mum spoke about his love for sweets. Ewan says he mainly eats sweets when he is bored. When his blood sugar control was better, one piece of chocolate would have a bad effect on his body, now because his control is not so good, he does not feel it physically when he eats chocolate. However he does feel bad when he eats sweets now, mentally. He likes to have good control and keep his HbA1c down because it makes him feel good about himself. Because that way he shows himself he can do it. He also then shows the health carers he can do it. This seems very important to Ewan, what the doctors think. "I used to go to clinic when it was down. I used to take it for granted when it was low. I don't like going to clinic now. I feel bad in myself and the doctors say it. I feel like I let them down. I mind they are there to help me get it down. I feel like I am wasting their time."

The other reason why Ewan wants to keep his blood sugar down is because he is worried about the future, the possible complications as he gets older. This worry is quite recent. A few weeks ago he saw a program on television, "one of the commentators was 26 years old and was blind in one eye and was getting problems in the other eye, and at the end it turned out he was diabetic". When mum says Ewan was really depressed for a while after seeing that program, I ask whether he did not know about these things before? Mum replies she tried to keep it normal, did not want to scare him. I ask Ewan whether the nurse did not tell him, when she explained him what diabetes was? Ewan says she did not, although maybe she tried to tell him, maybe he might not have been interested if she had told him. "I was interested in the gadgets, all new toys and what they could do." Mum adds that nurse Sally said that if they kept good control there would be no reason for bad health when older.

Whereas Ewan's control used to be very good (he is very sporty, a cyclist), since last year his blood sugar control has been up and not gone down. The reason is diet, he tries not to eat as much but finds it really hard, and this makes him angry, both because his HbA1c is high and because he does not look after himself. "It used to be I was in control, it feels now diabetes is in control." I ask Ewan what could help him, what doctors or nurses could do, as they wonder how to best encourage and approach teenagers.

Ewan: "I think it's up to me. I never thought how other people could help."

Mum helps him out: "You said you'd wish I was stricter with you?"

Ewan: "Yes. I wouldn't like it, but it would help. It would be difficult at the start but then it would go better. I just want to get in control again."

We discuss this further. How Ewan wants his mum to be strict but then he would tell her off if she would tell him not to eat something. When I reply —influenced by the team's talk, though mainly teasingly— "that's the mother's role" Mum smiles knowingly but says she does not really want to play that role, and that **Ewan is old enough now**. Ewan states that he just thinks it would be easier if it comes from someone else, and he would only be annoyed with his parents, not with the doctors, he wouldn't say that the doctors were nagging, because they have so many patients and that wouldn't be fair, but his parents have only him with diabetes, so they can take it.

I ask Ewan what he thinks of the Paediatric clinic?

Ewan: "It's quite good, everyone is kind. I don't like going anymore.... Because I worry they get angry if it is up."

Griet: "Are they ever angry?

Ewan: "One time Dr. Scot was angry, with Mum, that upset me 'cause I thought I'd let him down."

Mum: "**I find it very difficult being open with Dr Scot, he always picks me up on language**."

Griet: "How?"

Mum: "If I say 'there's been a wee bit of misbehaving', he says, 'wait let's not talk about misbehaving, nobody is misbehaving'. Or another time I said: 'I am appreciating how difficult it is for Ewan, to eat well, I try to feed him well, but those moments he doesn't eat at home, like lunch or when out with friends, I give him money for his food and I am trusting him. **I don't want that part of 'mother checking up and nagging and being blamed for nagging'**. John picked me up on that saying 'this is a Scottish thing, parents putting responsibility on their child'".

Mum: "**John just nullifies everything I say**, in front of Ewan, **while I care a lot and this whole family is involved with Ewan and the diabetes**. That's why even sometimes I send my husband, because I can't cope." —I probe her "cope with what?"— She specifies: "Cope with John, the clinic and being picked up on

language, because we all try the whole family. The only member of the household who doesn't get involved is Ewan's older brother Frazer, he cares a lot for his brother and he will always be there, but he has his own things to worry about."

While Ewan does not mind Dr. Scot or Dr. Caroline, he is always nervous when he goes to clinic, because "I'm going and try and tell them bad news again. I'd enjoy it more if I had good news". Ewan is afraid the doctors will be angry because of his bad control. "Dr. Scott when he was speaking to mum he was angry, I thought he was angry at me instead." Nurse Sally has never seemed angry, he enjoys most talking to her, as she has visited him at home to talk about diabetes, which is something none of the other health carers have done. It is important to Ewan that the health carers know him, "it makes it more comfortable".

We discuss the clinic further and I explain to Ewan the doctors' dilemma with young people: they can either be strict with young people and tell them what (not) to do, and then be thought of as nagging, or be friends with the young people and not nag, just make sure they keep coming, but then possibly being blamed later for not being strict enough. I ask Ewan what he thinks would work best.

Ewan: "A mixture of both: serious and not so serious. It would help for some people if they don't nag, but do let them know what they can and can't do. I would see it as help if doctors were strict. **I feel from my parents and the clinic they're not pushing me enough to help get it down.**"

I confront him: "But you know you want to get it down, so why is it not down?"

Ewan: "**But to remind me, to have it coming from somebody else.**"

Again I put it to Ewan that the doctors fear that if they are strict, the young people will stop coming to clinic.

Ewan: "As long as patients knew, if the doctor says I am going to be your friend but sometimes I have to tell you what to do."

Ewan then tells his mum he'd prefer if she were a bit stricter with him though it will be difficult at the start. Mum replies to Ewan that he is always good with her, when she is dieting, he'll say 'no mum, you shouldn't have this'. The conversation meanders on, how food is a huge temptation and though Ewan often starts with a clean slate, after a while he gives in and eats. When Ewan concludes: "it's up to me, I need to learn and

control it. It's my diabetes", Dad protests: "**It's not your diabetes, it's our diabetes**". Mum explains how she tries to give him a healthy diet: "get him to have his protein and carbohydrates. I try to give him variety. But Ewan's got quite a discerning palate. I ask him what he would like to eat. Like he doesn't like lasagne but he loves spaghetti bolognaise. As a family we eat quite healthily, low fat. We do always have pudding, but then the custard is low fat milk based. On the days when there isn't a pudding planned, Ewan will just go to the freezer, take something out and defrost it, whatever it is. I tell him, put it back, we're not having pudding tonight, but he'll just go ahead."

When I ask Ewan if his parents are proud of him, he stays quiet, does not answer. Mum is surprised, she tells him: "I hope you *do* know we're proud of you, and we love you, we love both of you always".

3. Lisa (15)

Lisa, a tall, cheerful and active girl. Liked by nurses and doctors because of her positive attitude. At clinic consultations with nurse Sally, Sally will tell her how pretty and tall she is and 'this girl is gonna be so successful and a model'. Lisa was diagnosed with diabetes when she was 3, so she 'has always had it'. She seems very relaxed about her diabetes, she does and eats what she wants, she'll say she eats 'shite' and mum will smile and say 'yes, you don't follow the rules'. During our conversation in the busy living room at Lisa's home, mum will stand in the kitchen doorway and listen and add comments, followed by 'I should keep my mouth shut'. Mum is involved with Lisa's diabetes, and mainly tries to do her bit by making sure that meals are taken at a fixed time. Mum mentions that it should be interesting to see that in non-diabetic households, it doesn't matter what time tea is. It seems this is a big effort for her in her busy household to eat at certain times. Lisa is a competitive swimmer, three evenings a week she will test her blood sugars before, during and after swimming to make sure she can perform well (to avoid hypos). This testing for swimming seems to be the only diabetes management she does. Although Lisa is clever, she is only 15 and she says she'll sort out her diabetes (start to take care of it) when she sorts out her life, when she goes to college. Now she just lives from day to day.

I am interested in why Lisa is so relaxed about diabetes and how she manages it. She is sporty but says she eats what she wants, pigs out. Though Lisa has had diabetes since she was three, she says she only understood what it was in secondary school, three years ago. I ask why then (assuming she had had a diabetes education session). "Because the teachers didn't notice, there are so many, so you start to look out for yourself. At primary school the teachers would notice if I was high or low, but at secondary school there was no one, so, now I know."[3] I ask if she knows what her HbA1c is at? She does not understand what I mean. Mum clarifies "the finger prick at the hospital".

Lisa: "Oh, I don't know, I think around 9.5, a bit high. I tried to lower it down but it doesn't work."

Mum: "It's confusing, when we first started, anything under 10 and they were happy, then it was between 7 and 8 and now 10 is fine again."[4]

Griet: "Why does it change like that?"

Mum: "Because at the start 10 is good, then it had to be lower, but in puberty 10 seems to be OK."

Griet: "Do you think about your HbA1c, like do you try to get it lower?"

Lisa: "It doesn't bother me. **You never know what to expect.**"

I quiz Lisa on this, she explains: you never know what it will be at the hospital, and what they will say. I get the impression that to her the HbA1c is something for the doctors, a test they do and they talk about. As she does not know what it will be, nor their reaction, it is something that does not concern her. She is relaxed about it.

Mum: "At the hospital when they say it's high, **you feel guilty, we think we're feeding them the wrong things. But it's her own fault**, 'cause I don't know what she eats all the time."

Griet: "You mean she is old enough now?"

Mum: "Yes, **she's old enough to decide**."

So Lisa goes to Macdonald's with her friends and eats more or less what they eat, though she sometimes does remind herself she has diabetes and won't have banana

[3] Instead of an interest in knowing oneself and caring about it, she phrases as if finally learning about managing herself in an illness she had for nine years, came about because she had to, as no one else would look out for signs of her being high or low. She learned about diabetes by watching a video.

milkshake, unless she'll have a one off and have a small one. What about alcohol, can she do what her friends do or does she have to be careful?

Mum: "You were in hospital once for drinking, that's when you had a litre of vodka."

Lisa: "Yes, or we drink some Smirnoff ice, but like my mum wouldn't let me have a Smirnoff ice in the house."

Mum shakes her head

Mum: "I am always aware, is she home yet and should she be eating something now."

I tell Lisa about this Belgian doctor I know (Dr. Dumoulin, see next chapter), who is very strict and tells patients what to do. He is friendly but if your HbA1c is 9, you would be hospitalised and he would insist you do blood tests etc. I ask what she thinks about that, if the team here would treat her like that. Lisa is definite, she would hate it "It (diabetes) would be made into a bigger thing". We talk about it and I explain why he does this and Lisa says she sees the point. Mum anxiously asks: "So is he very strict on HbA1c and does he think that 9 is too high and needs hospitalisation?"

Griet: "Do you worry about complications?"

Lisa: "They always remind me about it."

Griet: "Who?"

Lisa: "Sally and Dr. Scot."

Griet: "How?"

Lisa: "That I have to look after myself because otherwise I could get eye problems and..." [*Lisa talks like she is bored and yes they say it but she doesn't take any notice. Her tone of voice goes up and down, like she would be saying 'blablabla'*] "I thought they were joking, honestly for years I thought they were joking, only, recently I found out they weren't. Yes, it sort of makes you worry, when I'm older, things can take over. But I'm not bothered."

Griet: "When will you be bothered?"

---

[4] I see this as an example of 'learned helplessness': no motivation and confusion due to random feedback (which I'll discuss in Chapter 5). Mum is also quite worried when she hears that an HbA1c value of 9% is not at all 'good' in Brussels, rather a serious reason for action and concern.

Lisa: "When I'm in college education."

Griet: "So you'll think about complications and taking care later?"

Lisa: "Yes, in the future."

Griet: "When is that?"

Lisa: "When everything else is sorted. College, life."

Lisa: "By the time I'm older, they'll have found a cure, I won't have to take insulin anymore. I'm not doing any more research, 'cause then I find you can have problems with blood flow and all this."

I want to find out what she thinks of the clinic and whether she finds the approach helpful or would suggest something else.

Griet: "How do you like the clinic?"

Lisa: "I hate it, I hate going."

Griet: "Why?"

Lisa: "It's boring, they always say the same sort of thing 'Oh, you've grown' and then the doctor talks about HbA1c and…."

Griet: "How would you describe the doctors, as friends, doctors…"

Lisa: "As a teacher, I am more comfortable with Sally just now, because she is a nurse and she has diabetes herself. Dr. Scot knows what he is talking about."

Griet: "You're not comfortable because he knows what he is talking about? Wouldn't it be worse if he didn't?"

Lisa: [*laughs*] "He confuses me, he is more distant, he's a doctor. He tries to get me to eat the right food, he encourages you to do the right thing, but it's not practical."

Griet: "How do you mean?"

Lisa: "'Cause then he starts talking about the things I could eat and it's not the stuff I would buy anyway. I switch off when he starts talking about that, and telling me what to do to be healthy."

Lisa repeats that during consultations she won't listen, she thinks about other things and will just nod and say 'yes'; she doesn't understand what exactly Dr. Scot says, it is not practical, not something she can do and it is not very important. Her brother has entered the living room and followed the last part of the conversation, he mentions something to her and they laugh. She explains he mentioned some foods that sound very strange, as to

exaggerate. They all have the idea that what Dr. Scot suggests is so far from what she normally eats that she switches off.

Griet: "So what does he say then?"

Lisa: "Like he would mention food with the right carbohydrate, but then I think chips have carbohydrate, so I can just eat those."

Griet: "So he talks to you about it but you just switch off and that's it? He does not tell you next time 'aha you didn't do it so now…' and like he is strict with you?"

Lisa: "No, he's too easy. He's never angry or will never say like last time I told you and you didn't do it."

Griet: "Why do you think they are so friendly?"

Lisa: "To make you feel welcome. It is so relaxed. It's weird, it's homely but it's not. It's a clinic."

Griet: "So would you prefer them to be stricter, not so easy?"

Lisa: **"I think they are too easy on us, like the teachers, and you just don't do as well. They don't make you work."**

Griet: "Would you say that if adults are strict you respect them more?"

Lisa: "Yes. It's OK for the kiddies, but at my age, they should switch. People are nice, you don't pay as much attention."

Griet: "So when would you pay more attention to what they say?"

Lisa: "If they made it more clear **what they want you to do**."

Mum: "They are very laid back in Millness hospital, maybe they could do with a wee bit more strictness. **They care, it's just their approach**. There was first nurse Angela, she was very matter of fact, she would look at the results and go from there, and say, this is what we'll do. Then there was Jane and she was much more relaxed, and then Sally and she was the same, very friendly. They're very laid back."

4. So Many Others

Not much is left of our original E-fit of 'adolescents with diabetes in Millness' (as presented in the previous chapter) that forms the base for the care approach of the Paediatric team. Rather, I hope it has become clear that there is no standard 'young person with diabetes'. These young people are all different. Therefore, I wish to refrain from explaining the variations in how young people 'live diabetes' through larger, sociology-size social categories. Thus I do not specifically mention social class, family situation or gender as variables to analyze and find patterns. Both because health carers repeatedly told me there were no clear fault lines along these divisions, and also because in two years of home visits and interviews I did not notice any either.

As concerns gender, apart from boys 'generally' being more sporty (exercise is beneficial to diabetes management) and more private with their worries (playing cool) and girls 'generally' being more preoccupied with bodily appearance (weight can be 'tricked' by omitting insulin, injections can leave scars and bruises) and more apt to sharing problems, I did not notice any clear differences that would warrant me to say: 'boys are more... whereas girls tend to...". Though ample research has been done along these lines and gender differences have been found, I did not see gender as a legitimate distinction in diabetes management of the young people I met.

As concerns social class, of course young people's family (and friends) are extremely important to who they are. There is the general correlation of the type: the easier the family situation (i.e. happy, stable two-parent family, involved in diabetes support, educated, no financial struggles), the 'better' the diabetes management (both being healthy and being at ease with diabetes).[5] Especially family involvement is significantly beneficial towards a 'good' diabetes management. —While family involvement and stability can be found across social classes, I have to stress that stable two-parent families are quite scarce in Millness.[6]

[5] Psychosocial studies showing these correlations abound. To only mention some prominent articles in diabetes journals, see for example: Anderson 1999, Hampton & Skinner 2000.

While I do not wish to reduce or explain behaviour through standard categories such as gender or social class — as it would, as it often does, violate the richness of data and other subtle differences— I have shown 'dividuals' in configuration with each other. And as in a kaleidoscope, every part changes —Dr. Caroline talks differently from Dr. John, Lisa can be pigging out or getting ready for a swimming gala, Mum can be alarmed by a diabetes TV program or be thinking Lisa is old enough to decide for herself— and every combination of parts is constantly shifting. With every twist of the tube, we get a different picture, i.e. a different way of 'doing' diabetes.

Thus, instead of talking about gender differences or social classes, I talk about Ewan, Gavin and Lisa, and their parents. Ewan struggles, taking things, mainly diabetes very seriously, being hard on himself. His mum is very concerned and involved, though does not want to play the 'nagging mum'. Gavin is more relaxed, takes life as it comes. Though his mum might think he ignores her, he does what she tells him and he appreciates her support. Lisa is also relaxed, she will sort out her diabetes later, with the rest of her life. Mum makes sure the family eats at fixed times and Lisa is old enough to sort herself out. Thus parents are involved. Maybe the health carers do not help by exaggerating the opposition parents-adolescents. They almost push parents out of the caring role, to take it up themselves. While I strongly agree that a good, trusting relationship with health carers is beneficial to young people, this does not need to be built at the expense of the parents. Which at present happens by the team presenting parents as nagging, "what are they like?" —and here comes the friendly nurse or doctor who does understand and is cool.

Nevertheless, talking to Gavin, Ewan, Lisa and so many others, seeing them at home with their siblings and parents, I get hope. Hope after the feeling of defeat, the cul-de-sac I found myself in when hearing the health carers talk. These young people *do* care, and mainly they care that their parents care. They *want* adults —parents, health carers, teachers— to be strict with them, to be more directive, in fact, to tell them what to do. They will never openly like it, but it would make things easier for them in a way. Not without conflict, but this is necessary to grow from adolescent into adult.

---

[6] I will return to this in Chapter 5 when I discuss differences in 'doing diabetes' between Millness and Brussels.

Young people *do* care, and do engage and they need adults. They will say they nag, but in the next sentence they'll say they actually need it. It is a game: parents/ teachers, health carers 'nag', teenagers are annoyed, but they also like it, they want to be pushed. They often, like Lisa talking about school and clinic, mention how they regret adults don't push them, to get more out of them. Adults could pull them out of the lethargy and motivate them. Someone to wake them up and make them try harder. But they do need the initial pull and push from someone else, it is too easy for them to otherwise just be lazy. Yet they are often left to be lazy 'because that's how they are, they don't want to be told what to do'. Or do they?

I agree young people are vulnerable and need a lot of support, but I feel they also need something else: diabetes knowledge and help with insulin management. They need *education* and *motivation* so they can choose to engage with their diabetes and manage it.

***

3

A Brussels Health Carer

1. Dr. Dumoulin

> *Dr. Dumoulin proudly shows me the graph with the results of the Hvidøre study: Blood sugar levels compared between 19 paediatric diabetes centres across Europe.*[1] *The Millness centre is on top (highest) of the list (with the high blood sugar levels the worst result of all centres), Dumoulin's centre is at the bottom (best results). I ask Dumoulin whether he knows the reason for this difference in result; it is not the insulin regimen, is it? He replies "No. Yes, of course I know the difference". I ask further: "Is it follow up and education?" "Of course, c'est l'anthropologie."*

Early in this research project, Dumoulin became the mystery element. From the start, Scottish health carers mentioned his name to me as the only paediatrician (in the world) who gets phenomenal results with diabetic adolescents. But how does he do it? Nobody knows. The standard comment being: 'He is very secretive about it, he does not allow anyone to sit in at his consultations'. I took this first comment I heard about him positively, a doctor who cares about the privacy of his patients.[2] A difference in interpretation. What I saw as Dumoulin's respect for his patients' privacy, the Millness team took as secretiveness. In Dr. John's words: "You have to try and get to visit Dumoulin, it would be so interesting to know *what he does to get those results.*

---

[1] The Hvidøre study was mentioned in the Context chapter. Interestingly, while this international major study is primordial to Dr Dumoulin, (and the two other famous paediatricians I visit in centres in Gothenburg (Dr. Thomas) and Boston (Dr. Stuart)), as it is the tangible confirmation of the benefits of their therapy, the Millness team does not dwell on this study. If it is mentioned, they'll say that their quality of life results were the best (passing over the fact that their health results were the worst).

[2] The lack of privacy always strikes me in Britain, and though it provided me with the possibility to conduct the major part of my research, I did not stop feeling uncomfortable, attending consultations. Sitting in at consultations, and especially in training hospitals, is a crucial part of the medical education in Britain, where patients too seem to be used to a third person, trainee or researcher, sitting in the room.

Because... he hasn't really published on that. He writes on his 'recipes' (personalized insulin mixtures) but he doesn't write on *how he makes his patients follow* that."

Thus, to get such great results, it must be something he does during consultation. Why else would he not allow any observers? Consequently, I am often told: 'If only you could follow one of his consultations, see what he does, that would be so interesting'. A few months later at a Millness paediatric team meeting I triumphantly announce that I went to see Dr. Dumoulin and managed to talk to him. My biggest card, that in fact I spoke to him, well, he spoke to me, for four hours —a very long talk, in Britain it is a privilege if doctors can spare you 20 minutes— gets lost in their only interest: 'did you get to sit in in a consultation?' My negative reply that not allowing observers is a crucial part of his approach, in order to safeguard privacy and build confidence with his adolescent patients, is met by a look in their eyes telling me he has managed to delude me. Again he has maintained his secrecy. Never mind a 4-hour one to one conversation.[3] I guess the picture is becoming clear.

Another explanation, also often mentioned to me, is simpler: he does not actually get those good results. He must select his patients or tamper with the study cohort. In a word: he cheats.[4] I call this explanation simpler because it does away with the mystery of the first explanation. There is actually nothing special he does in consultations. This view puts the minds of the Millness health carers, who do not achieve such brilliant results, at rest. It means that they are not failing. It also lifts from them the onus of considering a change in approach in order to try and achieve good results with adolescents. The explanation confirms (their) 'reality' —briefly put on loose screws by Dumoulin's results— namely, that it is impossible. They accepted this years ago and instead of trying to achieve the impossible, they opted to be 'realistic'. This entails accepting the situation as it is: teenagers with diabetes are a conundrum. It is near impossible/ extremely difficult to get them to do a management routine, so near impossible to achieve a low blood sugar. Instead the health carers offer those things the adolescents do want, need and accept: support, a listening ear, and understanding. In other words, it entails leaving the biochemical, physiological facts aside for a few years and focusing on the psychological and social issues. The health carers are 'realistic': if

[3] In contrast, throughout a year of fieldwork with the Millness paediatric team, I never had a one-to-one conversation with Dr. John, the head diabetologist.

[4] I do not wish to say that he is actually accused of cheating, however, the idea comes up a lot when people mention him and his results. It is a tempting thought to solve the conundrum. However, it is not malicious, rather playful, or maybe even to stress the extraordinariness of his results.

they made demands on the physical level (like setting a low blood sugar target, to be achieved by routines), the adolescents might even reject diabetes and health carers all together. Only when the adolescents are mature and ready to take on self-management will the health carers pick it up with them. Until then, the health carers move with caution and try to give the adolescents what they are ready to accept.

Nurse Catherine attended one of Dumoulin's workshops on his 'recipes' at an international diabetes conference. She tells me that the general opinion of the audience was that 'it is too good to be true'. I ask about the 'it'? She explains: "'It': the results he *says* he gets with his patients." She says that many questions from the audience were very dismissive of him, not really believing that what he claims works. She continues: "He is very secretive, underhand, about how he does it."
Puzzlingly, the reason Dumoulin himself gives in his publications, the importance of privacy and confidence in the doctor-patient relation, does not count as a reason for the Millness team. They keep looking for something else.

When I asked Dr. John, the originator of this research project, what he expected from it, which questions he would like to see asked —I was careful not to say 'answered'— his reply somehow put Dumoulin central in my study.
"In Britain we have developed a conventional therapy: 2 injections per day, it's a hands-off treatment I'd say. Now Dumoulin on the other hand, has his patients on 2 injections a day but he lets them do lots of blood tests, follow a diet and sees them frequently, so he gives them intensive support. But, he hasn't written about this much."

I am on a mission. Off to meet Dumoulin, a composed and imposing éminence grise.

Our first encounter was telling.

First from afar. The international conference on paediatric diabetes, Siena 2002, a workshop titled 'The quality of care in children with diabetes'. I quickly gather that the prolific questioner in the audience is Dumoulin. He stresses that paediatricians have to discuss what they *do* with the patients. "We need a personalized follow-up, this means the same doctor for the same patient (Dumoulin follows his patients till they are 20 years old), the frequency of the visits should be 6 per year, not 3 as in many centres, and I use twice daily injections with personalized mixtures of insulin." On another issue he comes back to be precise: "We should not use the terms 'intensive' to mean more

than 2 injections and 'conventional' to mean 2 per day, instead we should use: 'multiple injections' and 'two injections' regimes. Because intensive therapy means the frequent consultations and 4 times blood sugar control per day." These two comments show me Dumoulin as a direct person, who likes a concrete approach. He wants clarity in terms: intensive therapy means more than the number of injections. His next comment shows his sensitivity and understanding. "It is important not to dice the patient as a salami: one slice for the doctor, one for the psychologist. In my consultations the patient is not asked to undress, if you are dealing with adolescents, you will never see them again. Especially for the many Moroccan immigrant girls among my patients, privacy is very important. It is also important that we adapt our education to our patients' needs."

Second: up close but not (never) personal: in the conference corridors John introduces me to Dumoulin. I tell him about my research, that I heard about his clinic and that it would be interesting to be able to observe how it works. Would it be possible for me to come? Dumoulin replies quite formally —I say 'formally' as the usual response from doctors I ask to interview is: 'of course, just make an appointment'— "Well, we'll have to talk about protocols. What it is you want and whether that's possible. Write me a letter and I'll send you my article and then we can discuss the protocol [*this word again, it sounds serious, what does he mean? Something all research should follow and which so far I have managed to avoid and ignore?*] and see what's possible." After this conversation I am not very hopeful I will ever be allowed to meet him. But I decide to go for it and follow the protocol as best as I can.

Brussels, Children's Hospital, January 2002.

I have been granted a meeting with Dr. Dumoulin! I have come prepared, done the reading and drawn up questions. I will tell him that I would like to talk to him about the *quality of care* for adolescents with diabetes, with key themes like education, knowledge, acceptance, motivation and action.

I have read thoroughly the several articles published by the Hvidøre study group on comparative research on adolescent diabetes at the 19 different centres. As mentioned before both the Millness and Dumoulin's centre are part of this group, and in the results league one is number one at the top, the other is at the bottom. In 1997 the Hvidøre comparative research article concludes that, as possible explanation for these significant differences between centres, there is a "need to look at whether there are **cultural** or **socio-economic differences** in the choice of treatment regimens." In August

2001 the group's research article provides more detail, stating, "The attitude of treatment teams, self care behaviours, education models and patient satisfaction, are all related to outcomes (blood sugar levels)". In November 2001 Hvidøre publishes another article reporting research results that show that "higher quality of life is associated with lower HbA1c" so "the effort to achieve good HbA1c: is now justifiable not only on clinical grounds but *also* on quality of life."[5]

After two years of interviewing health carers in several centres and countries and three years of reading diabetes research articles, I have the strong conviction that all professionals involved in adolescent diabetes (both health carers and researchers) agree that the major aspect of caring for adolescents is to *understand*, not to judge. [6] The difference lies in where they go from there. For some (like the Millness team) this seems to be the end point: adolescents don't do what you tell them to, you cannot force them, so you can not judge them for it and you can only be very understanding. Other health carers take understanding as the basic attitude towards teenagers and from there they aim to *educate* them on diabetes and to *motivate* them to work towards a certain goal.

Apart from all Hvidøre articles, I also studied Dumoulin's 1997 article 'A Belgian Experience' in which he describes in detail his approach to adolescents with diabetes, which proves to be very different from my experience so far in Millness. I am familiar with his main points by now, definitely since he stressed them again at the Ispad conference, four years after publication of said article. He seems to have found a formula that works. Why change it?

---

[5] This 'also' is very important, it takes the wind out of the sails of paediatricians waving away high blood sugars by saying: "yes but our quality of life results are the best". While these results (as any) can be debated, they do provide a powerful argument. However, it is telling that clinical evidence is not enough to convince medical professionals, they need 'quality of life' data (difficult to asses, being a qualitative value) before they might consider a change in strategy. Does this show they prioritise quality of life (what quality of life?), or rather that they use it as an important argument to defend deviant clinical results. Does this 'also' and new evidence mean they have lost the straw they were clutching on to, or, in the positive way, that they finally have the decisive argument (since quality of life is involved and this is their priority) to start to focus on attaining a low HbA1c?

[6] This is a happy fact. Contrary to the messages anthropologists of health and illness mostly feel the need to give health carers: look at the person not only the illness. In this case, the anthropologist's job lies rather beyond: considering where to go from this enlightened insight.

2. Diabetes Care

Dumoulin states that the HbA1c level (the mean value of all patients at his clinic is exceptionally low, 6.6%), is *not* related to the number of injections or sex or age of the patient. One of his surprising and bold statements is that it is not any more difficult to achieve good control in adolescents than in any other age group. This goes against all I have heard daily from the start of this research and he has the results to back it up. The HbA1c level *is* however related to the number of **clinic visits** (his patients see the same doctor and the same nurse 6 to 9 times a year: 1 hour doctor, 30 minutes nurse), and to the number of home **blood tests** (he calls it home blood glucose monitoring, (HBGM) his patients do an average of 111 tests a month, this is 3 tests a day). Though Dumoulin does not mention it [*does he take it as self-evident?*] more is involved than just doing blood tests. Linked to the number of blood tests is the act of **acting** on them, by mixing ad hoc the needed insulin and following a daily track record, being able to pro- act on exercise and diet. So it is not just a matter of testing blood, but of doing something with those test results.

With my experience of diabetes in Millness, I am intrigued when Dumoulin says his patients do three blood tests a day, in Millness most patients do 1 test a week or 1 a month, when something is wrong. Why don't they do blood tests? Health carers say: 'they won't do them, they don't like them'. Adolescents say: 'can't be bothered, they hurt, I hate them'. That's it. So, in my focus on quality of care, my main question to Dumoulin is: how does he do it? How come his adolescent patients do something that Millness health carers say is impossible to even try? Are Belgian adolescents different? Are Dumoulin's patients different? Is diabetes and its management seen differently in Belgium, as more serious? Are doctors seen differently? Is health different? Does Dumoulin *do* something (his secretiveness!) with his patients (like threaten, scare, order) to make them do it? I want to find out from Dumoulin and from his patients: how do they feel about this? Do they hate it but do it anyway, or do they deem it important themselves?

Having read his articles, I reason that for the Brussels adolescents to come to the clinic 9 times a year and do 3 blood tests a day, they must have 'acceptance' and 'motivation'. Acceptance that they have diabetes and that it affects them today and possibly later. Motivation to manage diabetes and keep blood sugars balanced. I deduce this by contrasting the situation with Millness, where health carers give as reason that adolescents don't manage diabetes, they don't accept the illness: the seriousness and the fact it can affect them now and later in life. Instead they forget about it, try to ignore it.

So how does Dumoulin achieve **acceptance** (of reality and seriousness) and **motivation** (to manage)? I presume that he achieves this by **education**. He writes that "successful glycaemic control in young patients depends mainly on the quality and intensity of diabetes *education* and *follow-up* by an experienced team in clinic and specialized nurses doing home visits" (Dumoulin 1997:6). He repeats that his "therapeutic success (depends on) the high frequency of visits and home blood glucose monitoring, criteria for insulin adjustment, allocation of diet and the quality of education and follow-up by the same doctor and nurse." This education seems serious; he describes how " patients learn how to adjust their insulin every day, according to retrospective glucose measurements and to use compensatory modifications, not forgetting adjustments to physical activity. (...) "four daily HbA1c measurements (are needed) to assess the action of 2 daily injections of mixed rapid-intermediate acting insulin."

Compare this to the knowledge of adolescent patients in Millness. They know that diabetes is 'a bit of your pancreas that does not work' and that you need to take insulin. They also know that when they are high they can react with insulin and, when they are low, they can eat sugar or take some artificial sugar. They know the mechanisms of the effect of food and exercise on blood sugar levels. But, between knowing the mechanisms (Millness) and fine-tuning the levels and monitoring and pro act on them (Brussels), lie two weeks of full time diabetes education, and at least three blood tests a day to be kept in a diary, with mention of extra sweets, activities, exceptions and physical states.

So my main question is: How do you achieve acceptance and education? Other questions are: Who is in charge of the diabetes, the adolescents, the parents or the doctor? When Dumoulin writes that "at each visit, the HbA1c level is measured and discussed with children and parents" is this discussion merely explaining or goal setting? I have in mind the sensitivity about discussing HbA1c values in Millness: you

don't want to judge the patients, not tell them off for doing badly, don't check up on them.

My interview with Dumoulin is different from all interviews I have with doctors in the UK, US and Sweden during this research. I presume that the aspects in which it differs already half account for his successful results. In the UK, knowing my time with the doctors is limited (usually between 30 minutes, one hour), I start the interview saying what I am researching and ask them questions on that topic. Once started, the conversation flows and I can throw in the occasional quick questions like 'how?' or 'how come?' to ask specification or check what exactly they mean. Mostly it is a cosy casual chat, between a medical doctor and an anthropologist. With this I mean that as the topic is quality of care and the doctors know I am a social scientist, they don't talk about the chemical aspects of diabetes, instead it is a chat in non-medical language about attitudes, culture and social issues. I go in with a general idea of which topics to cover, the talk runs its own course, and I come out with the doctors' ideas and position on those topics. Thus, in the previous chapters on Millness, there is hardly any biomedical information (on diabetes), as this was never mentioned, nor did any health carer find it necessary to inform me on that side of the illness. There, my questions about diabetes in adolescents generated talk about support. When I quizzed about medical details, the reply was to leave it aside until they came out of adolescence and were ready for it.[7]

Not so with Dumoulin. From the moment I enter his office/consultation room the roles are set. In his white coat, Dumoulin sits behind his impressive desk, filled with files and papers. I sit opposite him on one of three visitor's chairs. Behind me shelves stacked with publications, all major international diabetes magazines of the last five years, ready to be consulted. Though this is a consultation room —Dumoulin sees his patients here Monday to Thursday, 9 to 5— it looks like an office and I am reminded that Dumoulin is also a university professor. Paintings and pictures on the wall, filing cabinets, nothing that signals we are in a hospital, no medical apparatus in sight. Only after I have been in the room for three hours, I notice, because he points at it, that what I had taken to be a large table, covered with books and papers, is actually an examination

[7] Hence, the significant difference in tone of the Millness chapters (1 & 2) versus the Brussels chapters (3 & 4) reflects the different focus of the teams, thus underlining one of my major points in this dissertation.

bed "as you see, I don't use it." Dumoulin does not physically examine his patients, teenagers sitting in front of you "en slip" (in underwear) that's impossible. While "endocrinologists love their Tanner curves" he does not need to look at that and if there is a problem with puberty, parents will ask him to examine.

Compare this with the 'anonymous' consultation rooms in Millness. The rooms are on a rota so do not belong to anyone. They are all similar: linoleum floor, four plastic chairs, an almost empty desk with phone, examination bed with curtain around it, sink and waste bin /sharps bin, antiseptic soap, trolley with medical equipment: syringes, gloves, tools. You can go into room 1, 2 or 3; the only difference is the doctor. On entering the consultation you get your rather abrupt confrontation with 'medicalness', as the hospital entrance with gift shops and a coffee shop resembles an airport lounge (apart from the wheelchairs), corridors and waiting rooms are cosily decorated with paintings and easy chairs.

Now imagine entering Dumoulin's room as a patient. From the plastic baldness of hospital entrance and corridors, through the diabetes nurse's room (desk, papers, bookshelves, a computer and printer (where patients download their 2- month blood tests results from their meters), scales and height measurer) you enter the doctor's carpeted consultation room. You are not confronted with a place to undress, or a bed where you will have to go and lie/sit on at a later stage in the consultation. You can relax about the physical part; you can keep your clothes on, no curtain that can be pulled, no bed with green paper.[8] It is clear that you have arrived at a place of knowledge and that you are here to *talk*.

So am I. Though for the next four hours, I will mainly listen. And learn. A lot. Not by getting answers to my questions, but by being lectured. It only takes five minutes to make me feel like a school pupil again, I have to listen and take notes and give answers when tested, while Professor Dumoulin divulges his knowledge. As I sit down and put my papers and articles on the desk, ready to inform him what I do and what I would like to ask him, he asks whether I have a certain article by him. When I confess I did not come across it, and add, neither did I find this one, or that (articles I saw references of but could not get hold of), he spends the first 20 minutes going through his filing cabinet, and asks his secretary to make copies for me. I am getting

[8] Though at Dundee there are the attributes for physical examination, neither here are adolescents asked to undress to be examined. There is no physical examination. But the room's atmosphere cannot be ignored.

uncomfortable, time is passing and I am afraid our '30 minutes' will be used up by him handing me articles. When finally he sits down at his desk and I ask him again whether I can tell him what I do and what I am looking for, he suggests: "let's first go through this article of mine which you didn't have, because what I do is in there and it's no use to ask questions which are all answered in there." We sit at opposite sides of his solid desk, each with our copy of his article in front of us. I receive one-to-one tuition. "The first part you can read quietly at home" he goes directly to the second part, his treatment method, and word by word (this takes up 2 hours) he goes over it. Soon I realize that what I thought would be a quick summary will actually be the framework of the interview. I resolve to try and fit my by now burning questions in between his monologue, as soon as a related topic comes up. I am not successful. Whenever I throw in a "how?" or "why is that?" he either ignores it or says: "I'll tell you later", "We'll get there", "first this". At other moments I chance again and say that what I am interested in is the *quality* of care, possible cultural and socio-economic differences, as mentioned in the Hvidøre studies. No reaction. When he himself mentions how different his results are from other centres, again I jump in: so how do you do this? "Plus tard" (later). I feel like an unruly student, interrupting him.

At the same time though I don't want him to waste his precious time and since I don't follow what he says about biochemistry and physiology, I feel the need to tell him that that is not really my discipline. Thus when he first looks for his articles in his cabinet and embarks on the scientific side of regimens, I say half heartedly to his back: I am an anthropologist, so..." —to no avail. When he explains the workings of the pancreas and insulin by comparing the body to a car (muscles: motors, the insulin: petrol, kidney: petrol filter, the heart: petrol pump, blood vessels: tubes leading to motor, liver: petrol tank), —my car mechanics being as poor as my physiological knowledge— I get nervous fearing that at the end of his elaborate explanation he'll test me again and ask 'right or wrong?'.

Like he did before when he said, "many think that x amount of insulin works y amount of glucose. Right?" When I reply "yes" meaning, 'I am listening, continue', he triumphantly shouts: "Wrong! It is wrong, but many diabetologists still think so and publish on it, even now", he gets out a book to show me a recent article by an American diabetologist. "And I'll tell you why it's wrong, it's very simple, but they don't understand." Idem when he goes over the 'exam sheet' all newly diagnosed patients have to be able to complete before they are allowed to leave the hospital after ten days.

The sheet contains a whole week, with four injections and three tests a day to be evaluated, with account to be taken of extra waffles, physical activity, illness and restaurant dinners. It represents a fictitious week diary with blood tests. The exercise is to go over every result and determine how the next insulin dose should be adapted, in order to get a correct blood sugar balance. We go over three tests a day, every time we need to decide on what to do. Dumoulin: "The morning test is 11. What does that mean for the next injection? Long acting insulin should go up or down? Short acting insulin should go up or down? In the evening they will eat later, at the restaurant, what does that mean... " We cover an entire week of insulin management. Expecting a test again, I try to be alert and even cheat, I already look at the next line of numbers and doses, in case at any point he'll stop his explanation and ask: so which dose should the patient now take? I sweat. It takes us a long time to go through the page, but I am never asked to continue out loud on my own. Phew.

3. A Unique Practice

3.1 Dumoulin and Other Doctors

Let us go back to the 'they don't understand'. For Dumoulin 'they' are not only other diabetologists, but also endocrinologists, adult physicians and especially GPs. Dumoulin has been a paediatrician diabetologist for 30 years, he was the first in Belgium. For 20 years every summer he has been on diabetes camps with the children, where he saw the 'real diabetes', how it was lived daily. He teaches at the faculty of medicine at the University of Brussels. He is on a mission to spread his knowledge, as there are still so many misconceptions around. Hence his active questioning at international conferences and his fervent publishing. Hence probably also his tutorial to me, dedicating four hours to teach me the basics of diabetes. [9]

[9] In contrast, the Millness chapter does not feature an extensive interview with Dr. John, the head paediatrician of the team, because we never had a lengthy conversation. Probably because I never requested one, he never suggested one. A combination of factors. I was puzzled though that he did not suggest an informative talk on diabetes and how the team approached it, at the start of my research. I wanted to let the year of observation take its course, he probably wanted to let me get on with things, without interfering. Again, this 'meta story' confirms the other, the message of these four chapters on Millness and Brussels: the difference in approach. Dumoulin was clearly directive, educational and hierarchical with me.

Dumoulin teaches his patients and tells them that when they leave the hospital 10 days after being diagnosed, "you know more about diabetes than your GP". –When he starts his sentence "I explain to them…" and I ask "who, the GPs or the patients?", he looks indignant, pulls a face and continues "the patients of course, GPs are stupid, I don't talk to them." At the age of 18 his patients used to be referred to an adult physician (internist) and they would call him and complain: "Since I am with the adult physician I am being treated like a child, the doctor decides my insulin dose, while the paediatrician treated me like an adult". With Dumoulin, they had to decide their own insulin dose.

Dumoulin knows his stuff. Already in 1976 he started to screen his young patients for complications, checking micro albumen (sign of kidney damage) and circulation. The screening allowed him to be a lot more demanding for a low HbA1c, as usually paediatricians do not see complications, and only adult physicians are confronted with them when the patient is older. But Dumoulin is a paediatrician who is aware of and uncompromising about complications, which as I have noticed during this research, is exceptional. Dumoulin explains: "There are no pictures of amputations and foot injuries in paediatric books" He gets up and shows me a book with shocking pictures of damaged feet.

Dumoulin does not have a very high opinion of other doctors, he is sure of what he does and is quite dismissive of doctors who do things in other ways. He stresses how diabetologists and paediatricians still make such blatant mistakes on diabetes and even publish wrong basic notions. He shows me graphs of different insulins and explains how the curves are actually to be read, which is contrary to how most doctors do it "many doctors don't know that the real curve, the amount of insulin patients get, is actually the sum of the two curves, of long and short acting insulin, an error of doctors". With a firm stroke of the brush he crosses out the ten insulin type regimens on the bottom of the page "this is for imbeciles, it's wrong, I only use these two types". He is convinced that what he does works and so there is no need for change, he can dismiss other options.

There are a lot of 'fairy tales' around. For example concerning insulin pumps: "there is no point to pumps: the same annoyance (still needing finger pricks to do the blood tests) and they just add an extra prosthesis. How long do kids keep a pump?" he asks, inferring that they tire quickly of it, "it's a toy". Even if as a toy, I say, it could

change children's attitude towards self-management? "A toy for the doctors, not for the patients. Patients don't want to stand out, with a pump they stand out. Doctors think that even if patients don't have good compliance, with a pump they'll have better compliance, but that is not the case." I ask whether patients don't complain of having to use a *syringe*, a complaint very often heard in Millness: syringe: long needle, 'it hurts', and 'it's a syringe'. Dumoulin has another sure answer: "A pen hurts just as much as a syringe. It's a fairy tale that a thin needle would hurt less. If the needle is short, you hurt more."

Dumoulin stresses to me the difference between a diabetologist and an endocrinologist. The patients of an endocrinologist have only to take one pill a day, endocrinologists need to know and tell their patients. They treat their patients like patients, see them only few times. The patients of a diabetologist have to negotiate every day: they have to test their blood, think about their dose, and there are many psychological problems. Patients never have a holiday from diabetes. A diabetologist gets to know his patients and builds up a relationship with them. The diabetologist is a psychologist more than anything else. While the first part of diabetes treatment is technical, after that it is mainly other problems that interfere with self-management.

By now it is clear that Dumoulin is sure of what he does and of doing it in the right way. He has the experience, the patients and the results to prove it. At this stage in his career, a few years till retirement, no one will come by and make him change his mind. He is convincing and he backs up his statements with graphs and chemical facts. He does not expect you to just take what he says for granted, he'll explain why things are the way he says they are 'and I will tell you why'. Though I am sure that apart from car mechanics or those with a science degree, all his patients and parents must lose him somewhere along the way.

3.2 Dumoulin and His Patients

"First technique, then psychology"

"The important thing is to avoid complications."

When a child at Dumoulin's centre is diagnosed with diabetes, it has to stay in the children's hospital for a minimum of ten days. (In comparison, in Millness, the child is visited several times at home by a nurse). Mum or dad can stay with their child and live at the hospital. In those ten days the medical aspects are dealt with: making sure the blood sugar level gets stabilised, gauging the amount of insulin needed by the patient. However, the main goal of the hospital stay is education: learning how to give syringe injections, learning the principles of diet, learning how to do blood tests, and above all: learning how to monitor and adapt own blood sugar levels. Both the child and the parent learn, so they both completely understand the principles. After those ten days they take an 'exam': a sheet with fictitious blood tests of a patient over a week, they have to go through every results to decide what has to be done at the next insulin injection. This means predicting the future action of the insulin taken, allowing for future activities, mealtimes and the amount of food that will be eaten; on the basis of this reasoning, they can decide if they need to take more or less long acting insulin as normal, and more or less short acting insulin. The idea is that from the start, in ten days, they learn all they need to know about the workings of diabetes to be able to do perfect self-management. Dumoulin stresses: "In ten days: education towards self-management: **first technique, then psychology".**

The first consultation after diagnosis takes two hours, preferably with both parents, if only one can come, Dumoulin insists it is always the same: "I will not teach one and then repeat everything again to the other". Sometimes the child will not attend, so it is not frightened by the seriousness and possible complications of diabetes that will be discussed.

"The first visit, is about technique: the patients need to know more than their GP, and a medical student can sit in. After this, it is mainly psychology, and so, it's private. No one can attend these consultations, apart from me and the patient, and the family." Dumoulin tells all new patients the story of his most famous patient, Ziggy, a star soccer player in premier league. He got diabetes at 17, attended an adult centre, did not get good care, did not play well. The trainer wanted to sell him to another team. The team's sportsdoctor called Dumoulin, asking him whether to sell Ziggy? Dumoulin told him that he could play a lot better. Ziggy came to see Dumoulin. His treatment was changed. Ziggy got his strength back and started to train better to show that even with diabetes he

could play as well as the others. Then he won the golden boot, the next year his second golden boot. He became team captain and was bought by a foreign team for a huge sum.

Dumoulin has a 'standard approach' in his consultations. When I ask him about the consultation, he comes up with an elaborate, well-defined answer. Of the format 'my consultations go like this and this, I tell my patients, I always say...'. This is in sharp contrast to other paediatricians, when asked how they conduct their consultations, they would say: "it depends, we might do this, we'll have a chat, look at the test results showing the mean blood sugar level of the last three months...". Dumoulin's personality comes through and he puts his mark on his consultations, he has a formula, a product.

> "I tell my patients the story about Ziggy. To motivate and reassure them. To assure them they are in a good place here, even the best. Many patients wonder: if I had more money, could I get better care? I want to assure them that they get the best possible treatment and that it is not better in another place, on the contrary."[10]

> "I say 'it is said that diabetes is the first cause of death'; I say 'true when one is badly cared for, false, when one is well cared for'.[11] It is said that diabetes is the main cause of renal insufficiency: true when one is badly cared for, false when one is well cared for. It is said that diabetes is the main cause of amputation: true when one is badly cared for, false when one is well cared for. It is said one has more infections because of diabetes: true when one is badly cared for, false when one is well cared for. It is said that for women, being pregnant is more dangerous because of diabetes, true if one is badly cared for, false when one is well cared for.'"

---

[10] A personal note on Belgian culture: in this small country people often think other countries are ahead. Patients often might think that in America or other countries, there are more 'state of the art' treatments. It is telling though how Dumoulin makes a big deal of assuring his patients they are in a good place and receive good care. He must frequently get this question from his patients and thus people desire the best possible care. I have not come across this ever in Millness. Patients or parents or doctors mentioning this concern of getting good enough care or that somewhere else things might be better.

[11] Not a fluent translation but I want to keep the passive in the original French phrasing Dumoulin uses: "vrai si on est mal soigné, fau si on est bien soigné". Dumoulin uses the passive but I do think he mainly means: when a patient takes care of himself.

He recites this whole verse to me. It does make an impact. I had expected him to say one formula and then cut it short, saying: 'idem for amputations, renal insufficiency etc.' He says a consultation is like theatre, I think he likes theatre. I realize that even to me, he performed a one-man show, a performance, the script was ready and he knows it by heart, the only thing I had to do was to listen.

> "In the first consultation [*Dumoulin uses the word 'scéance' 'dans la premiere scéance' which fits very well in his 'theatre' and 'performance' terminology*] I tell the patient 'there are three reasons why one is badly cared for' the first because of a lack of money. This is never the case in Belgium but in Morocco [*half of Dumoulin's patients are Moroccan immigrants*] people are blind at age of 18 because they do not have the blood test materials. I say in Romania [*where Dumoulin teaches summer courses to paediatrican diabetologists in a newly established centre*] they would cry just to have test strips 'and you have them and don't use them'. Second, because the doctor is not good (that is the case here neither), third, because the patients do not follow the recommendations."

I am impressed. By using this formula 'three reasons why one is badly cared for' from the first consultation, a big responsibility for good control is put on the patient, since they get the materials they need and the recommendations from a qualified doctor. All they have to do is to follow his advice and guidelines. The message becomes clear to me as to all new patients: diabetes is not determining, it depends whether one takes care of diabetes and oneself. That is the decisive factor.

> "I always say 'one never has a holiday from one's diabetes'. I do not say that 'with diabetes one leads a life as **normal** as a person without diabetes, but I say 'as **competitive**, both physically and intellectually."

> "I tell my patients: I am not a magician but your child is young and could be cured from diabetes, but I cannot say when that will be. **The goal is to arrive at the cure one day without complications.** From the start I am very directive: to assure them and to motivate. I say all complications of diabetes**: it's not caused by diabetes but by the excess of sugar in the blood**."

4. How Does He Do It?

> "*After this, it is mainly psychology, and so, it's private. No one can attend these consultations, apart from me and the patient, and the family*"

My knowledge of how consultations evolve is based on what both Dumoulin and his patients told me about them. Contrary to some (e.g. the Millness team) I am not that curious to find out about any mystery practices in the consultations, as to me Dumoulin's results are down to his treatment strategies, recipes and personal approach, not to what exactly takes place during the consultation. Consequently, I never asked the patients explicitly to give me the scenario of a consultation. However, I think that both Dumoulin's words and the patients' words about him (see next chapter) make clear that his personality and psychological approach are a main factor of his success.

Dumoulin does not impose a diet on his patients, they can eat what they want, provided they take the correct dose of insulin. When I ask which dose that is, he replies: "I don't know, they have to conclude that from their diary, from their own history."

His overall treatment strategy is clear: the goal of all diabetes management is a low HbA1c, so as to avoid complications when one day a cure for diabetes will be found. He is one of the first paediatricians who started screening for complications; this also allowed him to be more demanding of a low HbA1c. The care he gives to his patients provides them with the two tools they need to be able to achieve this low HbA1c: education and motivation. Education of technique: how to practically achieve a low and stable blood sugar, once the patients know the technique, the consultation every 6 to 9 weeks serves mainly to discuss the HbA1c and locate any problems, but mainly to provide psychological support to keep going. So initially a huge dose of education followed over the next 20 years or more by psychological support to keep up the motivation.

Can Dumoulin be strict with his adolescent patients? Does he feel uncomfortable telling the patients it is not good enough? What about patronizing? What about patients

not wanting to be told what to do, will they stop coming to see him if he tells them off? —All issues that are very present at Millness, in fact so present that they shape the health carers treatment strategy. All my questions are swept off the table, given no relevance at all, by Dumoulin's standard argument: the goal is the HbA1c. A true Machiavellian case of the goal justifying the means.

So how *does* Dumoulin motivate his patients? That depends, both on the patient and on the situation. "A consultation is theatre: it changes every time. It's all about finding the right motivation, and there are different ways." To motivate, he shows his patients the Diabetes Control and Complications Trial (DCCT 1995) article that concludes that good control diminishes complications. He also shows all his patients eye pictures, which show a clear difference between good and bad control. These pictures go with the story of twins who got diabetes at 8. The twins lived the same life, everything the same, the only difference was that one was his mum's favourite and could eat whatever he wanted. At the age of 20, there was a clear difference in the eye pictures of both boys. The favourite had irreversible eye vein damage. Dumoulin also has horrible pictures of damaged feet and amputations, he shows these only to young adults who don't do any management, as a last resort to try and motivate them. "The important thing is that when things are still reversible, to react."

How does he achieve the fact that young people do blood tests 3 to 4 times a day? "The important thing is to identify **cheating**. So at every consultation, they have to bring their blood meter and download the data in the nurses' computer and we print it out." I am surprised by the word 'cheating', vividly remembering the frequent explanation by Millness nurses: "they don't lie, they tell you what you want to hear". Or even "I know they haven't taken their insulin and I beg them to tell me, but they don't, they say they took it". The word 'cheating' is never mentioned. In Millness there seem to be two realities: the nurses' and the patient's. Dumoulin talks about cheating: one reality, one world: the real one which has to be respected. Thus I ask "cheating? Do you say this to your patients, 'you cheated', to teenagers and adults?" Dumoulin does not make any bones about this. Matter of factly he confirms: "Of course. The goal is a low HbA1c. They have to calculate themselves the mean value in their diary, and if they don't do it..."

I tell him about the UK and the values of empowerment. About the importance given to being careful not to be judgemental and to be sensitive with teenagers. I add as my own comment that in the end however it seems young people are offered many things while nothing is asked from them.

Dumoulin: "Outside of this hospital, young people don't know any more what their duties are. They throw rubbish on the street, don't give up their seat to old people on the tram. Here, as doctor, I can tell them something. The advantage I have over parents is that towards the young people I do have authority, as doctor. The worst thing is weak parents, but then I play the bad guy, and I say for example that they have to come to clinic every week. It's about trust. It is necessary that the patient, that the ball lies in his court. I say: you can eat whatever you want, I don't give restrictions, so they're not able to come to me and blame me. It is up to the patient to regulate himself."

Griet: "What if a patient has a high HbA1c, do you get angry?"

Dumoulin: "I judge whether it will compel him or motivate him. I am kind, I am angry."

Griet: "What if a teenager, 15, does no management, and he has a high HbA1c and says he does not care, what do you do?"

Dumoulin: "I hospitalise him in case of hyperglycaemia, when they have a HbA1c of 9% or more. If they don't do blood tests I say 'you receive the blood tests strips for free, you have signed an agreement to perform 2 to 4 tests a day. So now, the hospital is stealing, you are stealing. Me and you, we have signed this agreement'."

Not only the patient is being dishonest, but in a way the hospital is stealing from the community and Dumoulin himself has signed something which is not being honoured, so he too is in bad papers. Thus Dumoulin stresses this shared responsibility between himself and the young person, they are in it together. He appeals to the conscience of the patient, if not for his own health, then so as not to make other people cheat. I will come back to this later in the discussion chapters (5 & 10).

Motivation is achieved by theatre, by adjusting and playing a role the specific situation demands. Being angry or being supportive. The doctor needs to be flexible, to read the situation and react. First of all he needs to know the patient and parents well

enough to know what will work with them. Whenever I ask Dumoulin about the atmosphere during a consultation, whether he is strict, judging or understanding, helping and advising, his standard reply is that "consultations are like theatre". He plays a different role every time according to the patient, the situation, and the mood. He stresses that it is the patient who decides the style, the doctor has to read it and adapt to it, not the other way around. "Every time, every patient is different. There is not one single strategy. It takes a year to get to know a patient (nine one hour visits). It's theatre, you enter in the skin of a character 'un personage'."

After Dumoulin's elaborate description of his treatment strategy and policy, I suggest to him that to me, the difference with other centres in the Hvidøre study group is very clear. However, as conclusion in their comparative research article the authors write: "To be researched are the cultural and socio-economic differences". I ask: "Don't they know what you do and how that differs from other centres?" In other words, that the main difference is down to the approach of the doctor and not so much vague 'cultural and socio-economic differences'?

Dumoulin: "The doctors of the Hvidøre group: they don't see their patients themselves, have students in the consultations, so no privacy, have very little time to spend with a patient, examine their patients and ask them to undress, [*To Dumoulin these are all clear differences to his approach and explain the difference in results*] and then they say that I select my patients, that I only show the results of the good ones, but in the second study even 51% of my patients were Moroccan immigrants".[12]

***

[12] Mainly due to differences in diet (sweet foods) and lifestyle, in general their blood sugar levels are significantly higher.

4

Brussels Young People

Dumoulin states his patients do three blood tests a day, in Millness most patients do one test a week or one a month. How come Dumoulin's adolescent patients do something that Millness health carers say is impossible to even try? Dumoulin has explained to me how he does it. But what do his adolescent patients say? Are Belgian adolescents different? Is diabetes and its management seen differently in Belgium, more serious? Are doctors seen differently? Is health different? In a word, how do they do it?

Similarly as for Millness, in Brussels I do not take social class as a variable, though interviewed adolescents spread across different social classes and family situations. Yet, I have to mention that the percentage of 'happy families' is higher in Brussels than in Millness: there are less single-parent families and an overall higher living standard. There is also less 'adolescent trouble': drugs, anti-social behaviour, truancy, binge drinking, teenage pregnancy, all issues that are daily in the news in Scotland. But I do not want to take the above as the explanation for the difference in medical results. It would be too simplistic. One could reason that if adolescents are 'easy' and not so troublesome and risk-taking, they need less support and definitely less discipline and hierarchy. Or is it because of the discipline and hierarchy that there is less troublesome or self-destructive behaviour? Does Dumoulin then just have easier adolescents to deal with? Probably. But why so?[1]

Easter, 2002. The moment of truth. After the extensive audience of Dr. Dumoulin in January, we agreed that I would send him the specifications of the type of patients, like social class and age, I would like to talk to, together with a letter for the

[1] As suggested by Nigel Rapport: could Catholic control (Belgium) versus Protestant individualism and laissez-faire (UK) offer some explanation? As a Belgian Catholic person I was never aware of control, though perhaps, if there is an individualist and laissez-faire base to the Millness diabetes care approach, that may be the reason why it so surprises (and alarms) me.

patients, asking for an interview. By analogy to my research in Millness, where I approached the teenagers in person after their clinic visits, I addressed the letter to the adolescents, 'Cher ami(e)', explaining the research and whether I could contact them for an interview. Having witnessed a year of contacts with, and letters to, patients in Millness, the tone of my letter was concordantly quite informal. Dr. Dumoulin 'slightly edited' (his words) my original letter. This new letter addressed the parents first, then the teenager: 'Chers parents, cher Dimitri'. The content and language was official. It first mentioned the Hvidøre study comparing different results in different countries, to then introduce my research, titled 'Study to understand the way in which diabetes treatment is lived' (my literal translation from the title Dumoulin had spontaneously assigned to my study: 'Etude pour comprendre la façon dont est vécu le traitement du diabète.').

After my initial surprise, like at the interview, at being thrown back in a quite hierarchical system that I had 'outgrown', after spending five years in non-hierarchical British society, university, paediatric health care and clinics, I appreciated his involvement. I also appreciated his decision to send the letters from the hospital, in his name, because as he said: "the patients obviously know me well". Whereas it might be his way to establish his position, it did provide me with his authority that, as I had gathered by now, was significant. He sent me copies of the letters that had been sent to the parents and patients. I then contacted the patients by telephone to arrange a meeting. This arrangement was in all cases but one done with the parents, even when the adolescent answered the phone, they would call their parents to arrange the visit. I was surprised; in Millness, all my contact had been with the adolescents, the parents would often stress that 'they would leave us to it', that 'it was up to their son/daughter whether they wanted to talk to me and when and where'. I am sure that this had something to do with the fact that the letter in which my phone call was announced was sent by Dr. Dumoulin, from the hospital. Two authorities. If Dr. Dumoulin has sent the letter, then this research and the interview was serious and of course they would be very happy to talk to me.

I visit seven of Dumoulin's patients (age 16-17), in all but one case parents eagerly participate in the conversation, some having taken time off work to be home. I wish to find out how the Brussels young people talk about diabetes and whether/ how this differs from their peers in Millness. Will I find that Dumoulin may say his patients do certain things, but in fact they do not do, or rather, yes they do them, but actually

hate it, they are forced. Or will they be relaxed about it and just be different from Millness adolescents all together? And what will they say about Dumoulin and his practices? Though, I already know it cannot be that bad, as —contrary to their Millness peers— they, like all Belgian patients, can choose to see any other paediatrician or GP in the country if they do not like his ways. I will find that the entire framework surrounding diabetes is different.

1. Managing Diabetes

1.1 Hospitalization

For all interviewed adolescents, life with diabetes started with 10 to 15 days in hospital after diagnosis, to adjust blood sugar levels, and mainly for education of parent and child. As Dumoulin says: "after those 10 days the patient knows more than his /her GP". [*This seems very severe to me, by now used to Millness routine where, in the frame of 'normality', hospitalization is avoided and only happens in case of serious low blood sugar levels; thus patients go home where specialist nurses will visit them daily, to give injections and teach them how to do it.*] 10 days is only the minimum: if the patient can show she understands the management mechanics by passing the 'exam', she can leave. For less fortunate children these 10 days can extend to a month, until they understand. From the start this disease and its management is thus put in the hands of the owner, the patient. She is responsible. Also from the start, it is very clear that there is a lot to learn, and unless one has mastered the new techniques, one cannot self-manage. So you become an expert, you, and your parents. And no one will know how to treat diabetes as well as you. You will know more than your GP, it will be in your hands. Of course you will see your paediatrician every six weeks, more often at the start to solve initial worries, to check up and to get information and encouragement. Despite the harshness of this long hospitalization period, I guess this is partly its goal. Its disruptiveness: it breaks up life into life before and life after diagnosis.

Like a rite of passage (Van gennep), in those 10 to 30 days of separation from the normal world, the young people or children are educated into new life-saving

knowledge, they master new rituals which will become twice daily routines. They come in as novices, are stripped of their former worldly body, get a new body with an altered permanent state, they are now diabetic, they are bodily altered by completely new practices invading their body: injecting syringes into themselves, for many a traumatic experience at first, then followed again by pride of having overcome an initial fear. Separation. Transition. Integration: they go back to their former lives, home and school, but with a changed body, with new skills, new knowledge. 10 –15 days have instilled these new routines and lifestyles in them. They have been trained, have been tested, have been explained, over and over again, they have passed the final big exam, and can then be trusted to go back to their normal environments and continue what they have learnt.

Gilles, 16, says how in the hospital he had already learned the 'habits' (he calls his injections and testing 'habitudes') so that when he went home not much was different in day-to-day life. When I ask Gonzague, 16, whether all the testing and calculating is not complicated, he replies it is at the start, "but after 10 days in hospital, it's easy, c'est automatique." This rite of passage brings home the message that this illness is serious, that it involves nurses, doctors, hospitals, and means a break with your former life. Harsh but efficient. I guess this initial hospitalization accounts for a lot. Not just for the extensive and detailed knowledge all adolescents display about their diabetes and its management, also for the rigorousness of their self-management, A consequence of this is the not questioning of it all, the acceptance of the disease and what it takes to manage it. Dumoulin's authoritative character plays a huge part in the fact the patients even accept the hospitalization in the first place.

My first 'Belgian' interview.[2]

Gonzague, 16, tells me his story of diabetes.

"In the morning I went to the hospital, they said I had diabetes and in the evening I returned with dad and my suitcase and I stayed there for 10 days." — I ask why? — Gonzague looks surprised: "To learn. Insulins." he replies.

[*I have asked a strange question, what's more, I questioned something. I will soon learn during this interview and all the others to follow, that people do not question things about diabetes management. People do not question doctors' or hospital decisions. This*

[2] All interviews with patients and Dumoulin were conducted in French. Sometimes to preserve the saliency I put the French wording between [].

is not because these people in particular or Belgian people in general do not question things, but because diabetes in their heads and conviction is something which is clear, serious, implies certain necessary behaviour and treatment, which is the right and established way and thus not questioned. In a way, it makes life with diabetes easier. Easier because it is not being debated and struggled with all the time. It is not negotiable. Sure, everyone one time or other struggles with the practicalities, the demands diabetes management makes on their time, lifestyle, day planning, freedom and spontaneity, but they don't struggle in being tempted to 'not do it', in ignoring it, in giving themselves leeway, in being a bit less strict one day. Compare it to being on a diet, this can prove a constant struggle between knowing one shouldn't eat that biscuit but allowing oneself anyway. Whereas if one knew one would end up in hospital at biting the biscuit, like a peanut bite to someone with nut allergy, though tempting, eating the biscuit would be ruled out, not negotiable. A straightforward and thus in a way easy situation. That is the way it is.]

I am surprised and ask: "You didn't mind?"

He looks at me, again not understanding what I mean. His mum lifts her shoulders. Silence.

I look at them encouragingly and explain further: "Like, you did not want to go home to sleep and go back in the daytime? Both Gonzague and his mum say: "It's obligatory". Mum adds: "Every night at 2 a.m. they would come and test his blood sugars". This 2 a.m. blood test does not rule out the option of spending the night at home to me, especially since testing blood is easily done at home and takes one minute and is one of the first things being taught in the ten days in hospital. But I do not wish to challenge further their religious acceptance of what the hospital says is how it is. No need to even think about that. As if to convince me even more that I should have no issue with this, mum goes on: "He has good memories of those days in hospital. There was a little boy there with the same thing, and his mum stayed there too."

In fact, despite the initial shock, most adolescents have good memories of the hospital days.

Stephanie, 16: "I was the star at the hospital, I could already leave after 15 days."

[*While 15 days seem to me even longer than Gonzague's 10 days, I understand the pride in both their voices, as they always have other less fortunate patients to compare with. I do not tell them that in many centres the patient can go straight home after diagnosis.*]

Alexandre, 16, is similarly proud: "Normally you have to stay a minimum of 15 days, I only had to stay for 10." Again I ask him why he has to stay, leaving some space for a personal reaction or comment that actually, that is much too long. In all seven interviews, this comment never comes. Everyone, teenager and parent, is convinced of the necessity to stay so long. Alexandre's mum explains: "We need to stay in the hospital, to learn the regimen. To learn to give injections, to learn the correct dosage." Her French words are 'On a besoin'. This translates not like 'one is obliged', but 'we need it'. We, the patient and parent, have the need, it is not just something the doctor orders us to do.

1.2 Parents Involved

Another consequence of the hospitalization is the strong involvement of parents in their child's diabetes. From the moment of diagnosis, one parent, usually Mum, stays with the child in the hospital for ten days. Together with her child she learns the routines, the testing, the calculating, the injection. Back home, she will continue to teach and help the youngster even when he/she is fully capable of managing alone. In almost all cases parents stay closely involved. They are active in the specific diabetes management: giving the injections, preparing the syringe with the correct dose and mixture of two insulins "he likes me to make up his syringe for him" and calculating the dose "two know more than one".

Parents also provide the wider framework in which to conduct the new routines. The lives of all families involved switched to fixed meal times. Rigorously. For most mums the diabetes of their child became a part time job, if not full time the first years. Mothers tell me how they were almost paranoid about doing things right, to give the right food at the right time. Alexandre's mum says how stressed she was at the start, she wanted to follow to the letter all they had told her in the hospital. Alexandre's diabetes is lived with and in the family. Mum: "He likes it when I prepare his syringe, we share his diabetes. Of course, at the age of 9, 10, he knew how to take care of them himself, but we don't separate, it is shared." I turn to Alexandre, a clever and very good-looking young man. He sits comfortably and listens to his mum. He agrees. [*No cringing, no excuses from mum of embarrassing him by saying this. No mum talking about how she*

nags and how she should leave him to get on with it. All things I have grown to expect after my experience in Millness.] This involvement of parents can in some cases go very (too) far: like Daniel's dad, an engineer, who has 'hijacked' Daniel's diabetes. Though Daniel is now 16, his diabetes is Dad's domain: on his laptop, Dad has designed graphs depicting the trends, the statistics, and the prediction. Daniel's diabetes has become Dad's hobby.

These young people's diabetes is mainly shared, managed and discussed in the family, 'done' at home. In Belgian culture the family unit is given substantial prominence: eating of breakfast and dinner together, all eat the same meal. [*I feel absurd stating the obvious, but it is different from what I observed in Millness: few family meals, each eating their own dish, where consequently, diabetes is also more shared out of the home, with peers.*] Words like 'nag', 'tell him what to do', 'it's his diabetes', never come up in our conversations. Instead I hear 'two can be more sure than one', 'two know more than one', 'we share', 'he likes it when I help him', 'we debate together about the dose', 'I would write his results in his diary'. The language is one of sharing, being in this together, enjoying company and support, taking it on as a task and making it more pleasant. Being a parent *also* in diabetes.

Compare this with the framework in Millness: 'it's his diabetes' 'he's old enough to get on with it', 'here I am nagging again' 'it is up to you'. The idea that there is one diabetes, one person who 'has' it and as soon as she is capable, she has to deal with it.[3] And do not tell teenagers what to do. Let them be independent, don't stifle them. They have to realize it is up to them and learn to deal with it. I would call this a 'hands off' approach. If parents would want to help or advise or remind, they feel guilty because they are nagging and interfering with their teenagers' independence. They are reprimanded by the health carers, as mollycoddling their children instead of letting them decide for themselves, and the adolescents (are expected to) take offence, phrasing it as their parents are nagging them, telling them what to do. Why this constant confrontation? Parents against teenagers: antagonism, fighting over decision power. Why not the harmony model: figuring something out together? Why are parents and teenagers, or teenagers and any older age group, seen as diametrically opposed? In

[3] Contrary to what may seem, and as will be discussed further (Chapters 5 & 10), this does *not* conflict with the patients being taught personal responsibilities for their diabetes during the initial hospital stay.

scientific discourse, in medical journals, in psychosocial research, adolescents are placed opposed to the rest of the world.

Of course in Brussels there is also confrontation between adolescents and parents, in some families more than other. But diabetes does not seem to come into this equation. And if it does, then not for long. Because from the start all involved know that this is something you don't play with. To be bold: it is like there is no such thing as 'teenager' in diabetes. Let me rephrase this: there is no such thing as 'teenager' *discourse* (discourse about teenagers) in diabetes. This as opposed to the deluge that swept over me in Britain from the start of this research. I am not saying there are no 'teenagers' in diabetes. They are present, both existentially and biochemically. But I am saying that the biochemical reality of diabetes, overrules the social and psychological reality of being a teenager. As if there is 'time out' of 'teenager' in the diabetes game, as if we are in a distinct sphere.

Gonzague's mum for example, was afraid that he would rebel, that he would not hang in, with the management. "But it still hasn't happened". To me it seems unlikely it will, as Gonzague is now 16, seems very mature, studious and proper, wanting to become an engineer, and in a way he is proud of his diabetes management. He takes pleasure out of knowing these things other people don't, of being on top of things. The mother of David (15) tells me yes, he rebels, but "never involving his diabetes". "For his diabetes, he does everything, he can be furious, but he always follows his regimen, religiously, that is extremely important to him." I turn to shy and quiet David sitting next to us and ask him why? "So I don't have to go back to the hospital". Aha, finally Dumoulin's strategy of hospitalizing everyone with an HbA1c of 9% or above comes up, though David is the only patient who mentions it. [*Following this policy in Millness would mean that half of all young people with diabetes, since they all have an HbA1c of 9% or higher, would be in hospital.*] Dumoulin has an effective stick behind the door, but he does not seem to have to resort to it too often.

Surprised at no rebelling, but sticking to the strict management routines, I ask all young people whether they at least do not find it annoying. Gonzague lifts shoulders: "ambétant?" as if I have asked him whether he doesn't find it annoying to brush his teeth in the morning. He does not know what to say "beh non, beh oui, sometimes, maybe, a bit." As if I have introduced a new theme in the field of diabetes, 'finding

things annoying' an unknown topic for discussion. [*While 'not liking' things is what both young people and health carers in Millness keep telling me as to why they do not test their blood sugars, let alone keep a test diary.*] 'Annoying' does not enter the equation of injections and testing. As mentioned before, these things seem to be non negotiable, they are important. When I ask why they test, apart from again looking strangely at me as 'don't you know?', they reply "it is important to test, to avoid complications".

1.3 'Because it is important'

Patients and parents, when answering my strange questions on why they do things or how come they don't mind, always answer with: "because it's important". A phrase I often hear: 'it's important for the HbA1c', 'it's important to keep the HbA1c low to avoid complications'. It strikes me, as in Millness I have never heard the term used by patients or their parents in connection to diabetes management. Then how come here it is stressed time and again?

Apart from the wider socio-cultural context, ideas on illness and health, on education and responsibility, (all of which I will briefly mention in the next 'Discussion' chapter), I think Dumoulin plays a significant part in this. By *doing* what (and how) he does: I mentioned the initial hospital stay, the strictness, and education. But also by *saying*: during our interview, he would start every fourth sentence with 'the important thing is' [l'important c'est]. Patients and parents have adopted the phrases. Is this indoctrination? I prefer to see it as being clear on what really matters and cannot be tampered with. No doubt, no negotiation.

Compare this with the phrase often spoken by health carers in Millness 'can I negotiate with you?'. I did not often hear the words 'it's important'. Never from young people, it is cool to be relaxed. Among the doctors adult physicians would use it, more often than paediatricians. The latter would use the phrase linked to psychosocial issues: 'it's important to be aware of the larger family issues, 'it's important to keep the adolescents coming', 'it's important not to nag'. —Actually, writing this now, I realize that the 'important' things in Millness are all linked to doctors' and nurses' behaviour and approach, things they have to keep in mind or have as goals. With Dumoulin, all the 'importants' have to do with the patient's actions, what he/she has to focus on and do.

Saying 'it is important', being motivated and trusting Dumoulin, also leads the young people to be content with their regimen. When I ask whether they might like to try a different treatment, they are definite: "I know what I am doing now, it works, so I'll stay with that." Confidence, acceptance, motivation. It was work at the start, now it is a way of life; you just have to get on with it ['faut faire avec', 'c'est la vie']. They have a routine now, not just their management at home, but also the relation with the doctor. All know what to do and how things work, it works for them, they feel good, they are healthy and on top of their diabetes. They do not worry about complications later, as they do what they can now. Later is very present in their diabetes-life, again partly through Dumoulin's screening and strict approach. Unlike many adolescents in Millness, of whom I often got the impression of racing with their 'eyes wide shut', not wanting to know now about later and possible risks. They'll deal with that when they get there. —But then, one could ask what future some of them, like for example Charlie, have to sign up to.

Another indicator of how important management was taken by some was the fact that Dad or Mum had taken the day off work to be there when I came to interview their child. Not so in Millness, where even if parents were at home, they would usually disappear into the kitchen, leaving their child to get on with it, not wanting to interfere or 'nag', or not interested, 'well it's her diabetes, I don't need to be there do I?' The Belgian extreme to that must have been aforementioned Daniel's (16) dad, the engineer who adopted his son's diabetes as his own hobby.

Though I sit at the kitchen table ready to ask Daniel about life with diabetes, I will not get to speak to him. Dad will take his laptop and give me a one hour lecture, illustrated with the personally designed Excel spreadsheets he maintains with Daniels' daily test results, the differentials, predictions, monthly overviews, probabilities and trends he produced from those. He has covered every possible outcome and variation one might like to consider with the type of data stored: curves of insulin use over days, compared to other months, compared to previous years. Dad's catchphrase would be "one has to follow the rules" ['il faut suivre les règles']. With rules, he meant the formulas of calculating the insulin dose and other formulas for every situation at any moment of the day. When one follows these rules, one does not have to worry, about Dumoulin, about complications. One combines the amount of food, the amount of exercise and then calculates the dose. Initially uncomfortable, like with Dumoulin, that

all interview time, would be taken up by the science and statistics which I was not really interested in, after half an hour I relaxed, taking this as Dad's interpretation of my 'study of the way in which diabetes treatment is lived in Belgium'.

I was also impressed. If an engineer can talk one hour explaining to a layperson the details of daily insulin regimen, there is a lot to say. It is a skill, a body of knowledge. The detail of this knowledge was new to me. During a year of observation and interviews in Millness no one (adolescents, parent or doctor) ever spoke to me about diabetes management like this. Adolescents or parents would usually mention management in terms like "30 (units, dosage obtained by turning the end of the insulin pen to '30') of the orange (colour of the pen that holds a certain pre-mixed insulin) one in the morning and 15 of the blue one in the evening, I think." If people took my 'wanting to know how diabetes was treated and lived in Belgium' as wanting to know this regimen, it was telling.

For some adolescents being convinced of, and accepting, the importance of injecting and testing, does not make the everyday reality of planning and thinking any easier. While many young people just say 'that's life', others get bored and tired. The 'not liking' or 'minding' comes up, not in the self-management practices of injections and tests, but in the issue of needing to plan ahead. Needing to know and think about when they will eat and how much, so they can calculate the needed insulin to cover it. "You never have a holiday from your diabetes" ['On n'est jamais en congé']. To alleviate this burden, Dumoulin allows patients, usually from the age of 18, to switch to 4 injections a day, instead of the classic regimen of only 2. Four injections a day allows more flexibility in eating patterns, means no previewing or planning and being able to 'top up' insulin with an injection pen. Dumoulin does not want to start children younger than 15 on it because he says you need to be quite clever and disciplined to do this. However, at the age of 18 when children have left the routine of school life and are starting university or work, 4 injections allows them the flexibility they need in that less ordered life style. Dumoulin proves flexible himself.[4]

[4] In the international world of diabetes he is known as firmly advocating a 'two injections a day' regime, claiming that perfect results of HbA1c can be attained with it. This to the disbelief and surprise of his colleagues. When they then hear that many of his patients are actually on 4 injections a day, this is taken as the explanation of his good results, and again, a bit as cheating, as he professes the 2-a-day everywhere.

2. Health Carer – Patient Relations

It has become clear that I cannot separate the young people from Dumoulin: he is in their diabetes, the main character in their stories: 'Dumoulin says it's important', 'Dumoulin says that I have to'.

Jean, dedicated father of Bastien, age 3:
"I myself would read and research all I could to know about diabetes and to see what we could do better, and as soon as I met Dumoulin, I knew he was a professional, and so we didn't look any further. In general, the great professionals are tough and uncompromising, they say: ' you do as I say, this is the way it is, and if you accept it you will have good results'. But he does not treat us as idiots who don't understand anything".

It starts with knowledge. This is deemed the essential element of a good doctor and from here the rest follows. Patients want expert knowledge: the doctor needs to know all there is to know about the disease: the biochemistry, the best treatment, the current research, the international debates. Dumoulin has this expert knowledge. His patients and their parents all mention how he knows all there is to know, how he is the best and most famous in the country. They hold him in high esteem. Some parents and patients were at another hospital with a different doctor before. They looked for another doctor, who knew more about the disease, or who was stricter and took things more seriously. This goes for different types of patients and parents, from insecure ones who need a lot of guidance and are in awe of the medical profession, to demanding managers who recognise someone who takes his trade seriously, such as Jean.

As manager in a building company, Jean says he is very demanding: "I can predict when something won't go well because not enough preparation has been done. However, when people start to just do things and not have high standards and when they even start to accept that things don't work well, that's just not good enough. When we start to take failure for granted, where does that end?" Jean is strict with himself and with others, we can expect him to appreciate Dumoulin's strictness, seriousness, and as he calls it, professionalism. However, we could also expect him not to want to be told by a doctor what to do. Does he not feel patronized? Jean: "He does not treat us like

idiots who don't understand anything". On the contrary, Jean feels taken seriously by Dumoulin because the expert himself gave him private tuition five afternoons a week during three weeks. Jean took half days off work for this, and made the two-hour return trip to the hospital every day. "Every day he would explain one case, with medical text and medical terms and he would discuss all the curves and the graphs." Again I ask whether he would experience Dumoulin as patronizing? I explain that this is a frequent argument used by health carers in Millness for not being too strict. Jean has no sympathy for this: "Dumoulin is hyper specialized, should he treat the patient and tell him/her the reality or should he hide things? I want to know what there is to know and I want it straight, I don't like 'we'll see'". He continues: "Dumoulin knows diabetes inside out, he is the best, he might even be too scientific, 'cause he knows diabetes as his pocket. With him we have all the information, we know how it works and what we need to do to keep him healthy and his HbA1c low." Again, does this sound like someone who feels patronized? No. It sounds like someone who is taking charge, who knows what he is doing: he has the best doctor he can get, that is a great asset.

As for David's mum, an ample and less sophisticated woman in awe of Dr. Dumoulin and his centre: "we feel safe because all is being tested and the staff know what they are doing". I do not think there is an issue with feeling patronized either. She appreciates the knowledge, the seriousness, the feeling of safety it gives her. She is happy with how approachable Dumoulin is. "If we are in doubt about the dose, or we have a question, we take the phone and we ask him. You know we can call him eh, Dumoulin."

While Daniel's dad calls Dumoulin and the consultations very serious, I ask if he ever jokes or chats, "No, it is very serious", Alexandre's family seem to have a different relationship with Dumoulin. Over the years he has become a family friend. Sometimes the whole family attends the consultations. These are mainly social chats. Dumoulin talks about funny things that happened to him when he was travelling the world for conferences or holiday, they joke and laugh a lot. Mum says they are very lucky to have Dumoulin: "He is a very good doctor. Very available, gives excellent advice, is very generous to every patient. He does not prevent people to live, he does not put any prohibition, he says you should live with diabetes 'as if one lived normally'. He is a true pedagogue, very psychological: he calls it the mechanics of diabetes, just like a car."

Does Dumoulin sometimes get angry during consultations, as he is so strict? Mum: "Never with Alexandre, Alexandre is disciplined, and honest. He does get angry with patients who exaggerate, they get hospitalized."

Honesty will be an often-mentioned trait in the interviews. I think they don't just mean 'not lying', but to say things as they are. Mum: "In the family, we talk honestly about things, about diabetes. Dumoulin says 'one has to tell the truth' ['il faut dire la vérité']. We respect each other, we are honest. Alexandre will not just fill in made up test results in his diary; he will just tell Dumoulin if he hasn't done a few tests. There are parents who cheat, with their children. For example they say 'we'll tell Dumoulin we did this and this', while they didn't. Dumoulin knows and of course he is angry with the parents: It is too important to play with this."

But what about those patients who have more difficulty in dealing with diabetes and its management. Whose HbA1c crept up in puberty and to whom planning and routines are a continuous struggle? How do they speak about Dumoulin? Do they resent him, because he is strict and tells them what to do, because he gets angry with them? No. They respect and like him. They talk about Dumoulin as an older friend. A friend who respects them, is there to help them. If he does get angry, it is because he cares about them and because they are not taking care of themselves. Again, there is no antagonism here, but collaboration. A relation with surely some tension and differences once in a while, but overall a bond, a being in this together.

Both Stephanie and Gilles have known Dumoulin for seven years, since age 8 and 10. They have lived their adolescence with diabetes and with an hourly visit to Dumoulin every four to eight weeks. Stephanie, a fashionable 'wild' girl, 16, has twisted Dumoulin around her finger obtaining a flashy blood sugar meter and even premix pens instead of 'medical' syringes. Her HbA1c is 8%, Dumoulin has said it should be 6%.[5] At the start she saw Dumoulin every month, now every two months, for an hour. Mum says he really takes his time for them, for all his patients. "He reads the whole diary, he gives advice. He also talks about cases 'that frighten', cases that push you over, that convince you to be more firm-handed." Does Dumoulin ever get angry with her? Stephanie: "Yes, he gets angry. Because I cheated. I was 12, 13 years old and

[5] In comparison, in Millness, an HbA1c of 8% would be considered to be quite good (towards the lower end of the range).

I just filled in some fake test results in my diary. And he was really angry." Mum: "He gets angry because it's important." Stephanie: "He says he is different with every patient. With me he plays the paternal type ['Avec moi il joue le paternel']." "And you take that?" Stephanie: "I have no choice". I check again: "But he gets angry?" Stephanie: "Yes. Sometimes I went completely red and I was almost under the table. He was showing pictures and I did not want to see them, but I had to look, feet and eyes, horrible things. And yes, then I thought: phew, this is serious."

Gilles, 16, a bright and cheerful young man goes to see Dumoulin every month. The last years his HbA1c has been between 7 and 8 %, which "is a bit too high, it should get better"; he wants it to get lower, so he sees Dumoulin often and gets his help. Dumoulin is not too concerned about the HbA1c, he says Gilles needs to have patience; the important thing is that he does not go hyper during the day. Gilles: "Dumoulin says I have to think more, and think in function of what I do. In the diary I have to write what I eat, exercise. I am afraid to push up the insulin too much, and get a hypo, but he says I should not be afraid to take more insulin. Yes, he says I have to think more." How does he mean? "I have to look at previous days, like when I ate potatoes then and before I was so high or low, how much was I after that. So I have to go back in time and think analogically. (...) I see him every month, we have a good communication, we crack some jokes." Does Dumoulin get angry? "Sometimes. When he says I haven't listened to him or when he has explained everything and I haven't done it." Do you mind? [*My 'minding' question again.*] Gilles: "No. It's necessary to get angry once in a while, otherwise he would not have results. He has to get angry otherwise kids don't realize it is something serious. He adapts with all patients, when I was small he was more guiding, now I think more. He always writes a 'last remark' in my diary, something I have to focus on or pay attention to the next month. He says he cannot always tell me any more what to do, what I have to pay attention to, I have to do it myself. But he did say I can stay with him till he retires."

This sounds strange but beautiful to me, these words being spoken by a good looking young man, pony tail, independent, who knows where he stands in life. He is not at all annoyed with Dumoulin, or ashamed, it is like he has a wise old friend who gives him advice, and he likes talking to him. Gilles: "Other doctors give their patients fixed doses of insulin, they can't move. It's good to give responsibility to patients; this way deciding on the dose becomes a habit. Now, before every meal, I take 5 minutes to

think." At the end of our conversation Gilles stresses that I have to know that: "People like coming to see Dumoulin. They come to Dumoulin not like 'oh no, I have to go and see a doctor', a stranger I don't know, for a problem or diagnosis, but: 'it's fun to go', every month, to chat. You're going to see a friend, an acquaintance, like a visit."

It has become evident that Dumoulin, through a sustained and frequent contact with his young people patients and their parents, offers them security and clarity. Clarity on diabetes, its management and complications. Could I state that, in contrast to the Millness team that stresses the need to be realistic, Dumoulin offers his patients 'reality'?

Dumoulin tells his patients what to do, yet, they do not feel patronized. Could this be because with him they share the same goal, a goal they have to work towards, and are motivated to achieve, every day? One is the expert and gives advice, the others become experts themselves. Could it then be [*still trying to understand the Millness 'patronizing' monster*] that you only feel patronized when someone tells you (to do) something you are not really interested in, you do not want to know about? Is the difference then whether or not one values knowledge and advice —if one does, one is eager for more information, if not one feels patronized— and one acknowledges expertise: the fact that someone knows better, so you want to learn from that someone?

***

5

Discussion

Doing Diabetes Differently

We have seen two different approaches to care of young people with diabetes. I have described *diabetes being done*. Scenarios of clinic consultations and accounts by health carers and young people have shown us diabetes in action: a combination of people, bodies, ideas, discourses, scientific 'facts', likes and dislikes, necessities, etc..
The medical 'outcomes' of these two ways of doing diabetes differ significantly.[1] The four previous ethnographic chapters have attempted to show why.

In this chapter, in addition, I suggest we might find an explanation for the difference in outcomes, by looking at it from a different angle: not at *how* management is done, but at *who* does the management. Realizing I may be contradicting myself —as I just wrote that people and bodies and ideas and medicines *did* diabetes, together— maybe this shows the limits of such an 'in action' approach: it is noncommittal and non-agential.[2] And perhaps noncommittal is not entirely appropriate in cases where lives are at stake. Where responsibility, engagement and ownership are relevant factors. Are these then the specific qualities distinguishing human actors/actants from others?
Thus my question is: who manages diabetes?

The answer could be very simple. In Brussels all manage diabetes together: the young person is the main player but he does it to a large extent with his family and with Dumoulin. In Millness: no one really actively manages diabetes, because no one 'can': the parents say it is up to their teenage children, and it is the health carers' job; the health carers do not want to put the onus on the adolescents, as life is already hard enough, and they cannot be strict as young people do not want to be patronized. The young people think they are doing fine. Management is like a hot potato being passed

[1] As evidenced in the Hvidøre study mentioned before (see Mortensen et al 1997 and Danne et al 2001).
[2] In Chapter 6, I discuss theories informing actor-network and performative approaches.

around, maybe this is not a suitable time to eat it. Let it cool down. As Dr. Caroline said: "You just pray they get through adolescence without too much damage".

1. Empowerment

Of course things are not that simple. We have seen how a discourse informs the hands-off approach in Millness. The team talks about 'supporting' and 'negotiating' instead of 'patronizing'. This fits in a broader discourse in chronic illness management on a theme that over the last ten years (and especially during the period of fieldwork 2000-2003) was, and still is today, omnipresent in diabetes care: patient empowerment. As this topic has been extensively discussed by medical doctors, health psychologists, sociologists and anthropologists, here I merely situate it in order to inform the following discussion.[3] In 1985 already hinted at by the World Health Organization defining health promotion as "the process of enabling people to increase control over, and to improve, their health", true 'empowerment' literature spread over health journals since the 1990s. In diabetes care the concept was defined by Funnell et al (1991):

> "Patients are empowered when they have the knowledge, skills, attitudes and self-awareness necessary to influence their own behaviour and that of others to improve the quality of their lives."

This approach recognized the unique role and responsibility of the patient in the daily treatment of diabetes in contrast with the (hence) traditional medical model based on adherence and compliance. Dr. Robert Anderson (1995), famous advocate of patient empowerment in diabetes care, brings the difference between the two approaches down to who ultimately is in charge of an individual patient's diabetes care (1995: 412).[4] Whereas in the traditional model final authority lies with the health carer who prescribes —the patient complies (or not)— in the empowerment model the patient is in charge —the patient learns how to make informed choices about diabetes care. The patient is the expert and thus "to be viewed as a responsible and active decision maker in diabetes

[3] An elaborate theoretical and practical overview and discussion of empowerment in adolescent diabetes care can be found in Greene (2000).

[4] Anderson and Funnel (2000) base patient empowerment on three diabetes-specific psychological principles: 1, the patient and his/her family are the locus of control: 99% of diabetes care is self-administered each day; 2, diabetes health care team provides age appropriate expertise and information, and non-judgemental psychological support; 3, any behaviour change is more apt to be made and sustained if freely chosen and personally meaningful.

care" (Ibid.). Both medical and psychosocial research on the medical and motivational benefits of self-management education and autonomy in diabetes care abound.[5]

Then why do I feel uneasy about 'empowerment'? While there is nothing wrong with the content as it is described above, I feel there is something amiss with the term, or rather, how people fill the term. As said before, things are not that simple, they are *made* complicated.

1.1 Millness

Firstly, the term leads to confusion.

(1)
An exchange in a workshop at the ISPAD (International Society for Paediatric and Adolescent Diabetes) 2003 St Malo conference, on the benefits of the Continuous Blood Glucose Monitor (a small technological device on which one can continuously read one's blood sugar levels):
Dr. John (Millness team): "What we are left with is an educational tool. The biggest problem about that, is not with the health carers, but is the patients, who don't want to be taught."
Nick, a German paediatrician, disagrees: "But John, we also have to empower our patients, in the long run they will be able to make educational decisions. It is not just an educational tool."
Dr. John jokingly replies: "In my patients, that would probably come down to empower them to switch the thing off."

(2)
At the same conference, during a workshop on 'empowerment', Dr. John comments: "I go with the empowerment model, but there is a problem: adults are different from adolescents. Adolescents decide to put themselves at risk. And health carers are not

[5] See for example a review article on such studies by Clement (1995), also Williams, Freedman et al (1998). See also Brown (1996, 1997): articles on empowerment and its implications for diabetes education and patient-health carer communication by a Scottish diabetes nurse specialist.

allowed by society to let that happen. Like boy racers: the last thing you want to do is to tell them more about the car, so they can go even faster."
The workshop convenor replies: "The question is: how do you race faster in a safer way? As health care professionals we need to be better educators."

(3)
Nurse Sally tells me Dr. John is not keen on empowerment, as it puts too much onus on the patient.

Three iterations that show the confusion this open-ended term travels with. It seems that the Millness team, Dr. John specifically, employs an 'all or nothing' strategy: empowerment means giving 'power' (control, decision power, authority) to the adolescent patient. He does not see it as a combination of different things: responsibility supported by education and counselling. Another term open to interpretation is the 'quality of life' as stated in Funnell's definition, whereas, especially when young people with a chronic illness are involved, quantity (of life) should at least be on a par with quality. While the Millness team is not as cynical as some other doctors saying: "empowerment: you mean we don't give a shit and let the patients get on with it?"[6], I guess this quotation shows where the confusion comes from. The empowerment model originated in antagonism to the traditional medical model with an authoritative and prescribing health carer, and thus many (mistakenly) take it to mean the exact opposite. No more authority or paternalism, the patient makes his/her own decisions.

However, while doing their all to steer clear of patronizing, one might suggest that the Millness team does exactly this. By *constructing* realities, such as 'adolescents' and 'diabetes'. Talking about adolescents, the health carers seem to make 'adolescents with diabetes' into an entity on its own, attributing several characteristics and behaviour traits to any member of it: 'add water and stir' formulas. Adolescents do not want to be told what to do, thus we health carers will not tell them what to do, we will listen to them and understand. However, by following their 'life coach' scenario during consultations, the health carers fail to address many adolescents personally. Many adolescents do not engage in the consultations, nor in their diabetes management.

During fieldwork, in clinic consultations, I did not hear one young person ask about their management and what they could do themselves to make things better.[7] This as opposed to other centres (not only Dumoulin's, but also in Boston and Gothenburg, see Chapter 9) where young people debated with the health carers and were accountable for their diabetes. I suggest that the main reason they do not take charge of their management is because they are not really given the chance. They lack the education to know what to do and the motivation to know why. They get support and understanding, but they do not get a task. Instead of self-empowerment, I would call this, borrowing a health psychology term, 'learned helplessness'. This occurs when "the organism learns to be helpless as a function of *random* feedback", in other words, when you are in a situation over which you have no control, you are unable to actively learn new responses, as you have no way of knowing what is better (Kaplan 1993: 175). Hence the importance of 'coping strategies': knowing what to do in which situation, and the effect of that action.[8]

A second issue I have with empowerment relates to the broader social context in which the term acts.

Terry Wogan's morning BBC Radio 2 show, commenting on the launch of a new healthy living guideline.

Wogan: "You are responsible for your own waistline..."

Sidekick: "What? Me?"

Wogan: "Yes, it seems you are, not the government, not the doctor, not the NHS..."

Sidekick: "Blimey, what will they say next?"

---

[6] As a cynical diabetologist commented to empowerment-advocating nurse Brown.

[7] In fact, one girl did take charge of a consultation in Millness, asking the doctor plenty of questions she had prepared in her notebook. She was an American student studying in Millness for a year. At the meeting afterwards she was labelled 'a freak', 'neurotic', until one health carer said "no, she just likes to take good care of herself".

[8] A study found a close association of learned helplessness with poor control of diabetes. Many young people with diabetes feel they have little control over their lives (Kaplan 1993: 195).

Charlie's mum, as we saw before, is fed up with him ending up in hospital every weekend and thus tells the doctors they have to sort him out.[9] Parents —at their wits' end, or out of habit? — put the disciplining of their children into society's hands, with professional adults like teachers and health carers. Lisa's mum to Dr. John: "You tell her that, I tried." Lisa is not worried when her control is high, that is the doctor's fault, it means he does not give her the correct insulin dose.[10] People do not seem to wish to take care of their own body and health. They do not feel responsible for it, or concerned. Not enough to take it in their own hands. Or is their trust in the health carers so solid? "From the cradle to the grave we'll take care of you." This means that if the health carers do not care about health, no one does.

"Dr. John is not big on empowerment, it puts too much onus on the patient." His solution seems to be to put the onus nowhere, to leave it aside for a while. Why not put the onus on adolescent, parents and health carer together? Are they not working towards the same goal? I remember my astonished reaction in a diabetes team meeting after listening for another half hour about how they could 'maybe try to get a message across that they might want to ask the young people to, if possible, do a few blood tests a week', "they'll never do it", "they'll quit all together". As if I was listening to ogres trying to trick young people into something evil, rather than health carers discussing how to improve young people's health. Having just returned from my interviews with Dumoulin's engaged patients made the contrast even bigger. For fear of still not having stated the obvious after so many months of interfering fieldwork, I share my confusion with the team: "Why would I be angry if you as my doctor told me what to do? Are you not working towards my well-being? How can I mind that? Is not the whole medical practice there to make me better? Isn't that why I go to the doctor, he helps me and advises me?" Maybe this was a clash of cultures again. Speaking from the Belgian health context I know from personal experience, and observed in practice in Brussels, I see the Millness approach as topsy-turvy. Psychology has taken over physiology/ biology. I never thought I would feel the urge to tell medical doctors not to forget about the body.

---

[9] See vignette before Chapter 1.

[10] I could expand: when a child dies after being abused by her parents for years, the papers write on how the system has failed her (not about the parents) and a witch hunt is launched to punish the civil servant responsible. When primary school teachers talk to parents about their child being violent in class, parents angrily say "it's the school's problem, the school should sort it out".

As mentioned before, things are *made* complicated in Millness. Though health carers keep stressing the importance of being realistic (and thus not have 'utopian' goals), it seems there are many realities, or rather, the Millness team *constructs* realities.[11] Young people are to a big extent allowed their own space and world in which they have their ideas, wishes and reasons to do (risks, drugs, drink) or not do (blood tests, injections) things. For example 'they are not taking risks, they experiment'; 'they don't lie, they tell you what you want to hear'. Their adolescent world (as they are a fixed entity on their own, they live in their own world and ideology) is accepted as a reality by the people in the other world: adults, specifically health carers and parents. In Brussels, I hear no unifying discourse 'adolescents are...', adolescents are not seen to live in another universe. Yes they have specific problems, through which they are guided, and counselled, but this is a stage, it passes, and all the while they stay in the one same world —of, among others, physical facts. In Millness, adolescents seem to be allowed, by doctors and parents, to move outside this world of physical facts until they are ready to come back and start to face reality again.[12]

1.2 Brussels

Are things then not made complicated in Brussels? I would say diabetes management there is quite straightforward, which does not mean not difficult. But what diabetes *is*, what its risks are and how it should be treated, is known by all. I guess it helps to have 'the way' established.

Is Dumoulin then a patronizing doctor imposing a treatment on his young patients that they have to merely adhere to? In other words, is he still stuck in the

[11] Are they then the true 'performance theorists'? (See Chapter 6).

[12] Indeed, listening to health carers talk about adolescents, I got the impression they were an exotic tribe; you had to know very well how to deal with them before you could venture out there to meet them. To my surprise, as almost 20 years later I do not feel very different from the adolescent I was, not knowing whether this meant I had really become very old, or again whether this was mainly a cultural (national) difference. In the UK, though in general adolescents are derided, they are also feared and ultimately admired. They are the future, their taste is fashion. So often I noticed adults wanted to be accepted by adolescents, wanted to be thought 'cool' (read 'young', read 'counting in society'): 'I am just nagging', 'I hope I am not patronizing', 'gosh you must think I am old'. Why this baiting for sympathy? Society

traditional medical model? On the contrary, I would say that he practices true 'patient empowerment': giving the patient extensive education so he can take up his treatment. When I ask Dumoulin what is the correct insulin dose for the patient, he replies "I don't know, the patient calculates that every injection time according to his diary." Dumoulin keeps telling Gilles he will have to think more for himself, as Dumoulin cannot always tell him what to do. His young patients (and their parents) are engaged with their illness management, and take care of themselves. Dumoulin achieves this empowerment by *what* he does: education, hospitalization, counselling, long consultations, but that can only work by *who* he is: a medical doctor with authority and a good psychologist. He combines both, understands the importance of psychology, but does not lose out of sight that he is first and foremost a medical doctor. 'First it's technique, then psychology'. And he is flexible: he plays theatre, he adapts to the patients needs of the moment. Does the patient need strictness and a firm hand, he will give it. He will even gladly play the policeman if parents have difficulty being strict with their teenagers. —Compare this to Millness where the team makes a point of siding with the adolescents "What are your parents like eh?"; "Parents nag, I do not want to nag". If Dumoulin's adolescents need support or understanding, he will give them that. Performance, theatre; but heartfelt and engaged. I suggest Dumoulin combines both the medical model with power to the doctor and the empowerment model (interpreted as) with power to the patient: a working together of doctor, patient and parent. Why should it be either/or? All have the same goal, collaboration seems the straightforward option. Thus a caring by sharing.

Is this not also what Millness does? I guess the difference lies in *what* is shared. While with Dumoulin it is mainly a sharing of the task at hand, in Millness the stress lies on sharing the burden of the illness. What Millness patients and parents appreciate most about the health carers is that 'he knows what it's like'. Dr. John knows that diabetes is difficult to deal with. He understands that people cannot just change their lives, and he does not demand too much of them. Patients desire and expect from their doctor empathy, an understanding (of their life situation, rather than of their illness). In contrast in Brussels, patients and parents tell me with full admiration time and again how Dr. Dumoulin is an expert and professional: he knows diabetes, and can tell them

---

feels it has to adapt to them, give them what they need and want. Not adolescents who also have to grow up and ply to what exists. A one way traffic.

what to do to take care of it. The main thing patients (and parents) expect from their doctor is information and treatment.[13]

While in both places there is a symbiosis between patients (parents) and doctors, i.e. the 'perceived' need of the patient shapes the health carers' approach, there is a difference in balance. In Millness the seesaw is heavier on the patients' side, the team labours at finding out their needs (and mostly wants). In Brussels Dumoulin is heavier than his patients: he defines his patients' need and decides the content of the relationship: knowledge, treatment and understanding.

2. Care

"He careth for us that knows what is fittest for us."

1676 HALE Contempl. I. 183 (OED)

Ethical philosopher Goodin (1997: 321) writes that paternalism is morally permissible in cases when people "would not have a chance to benefit by learning from their mistakes". This is in cases where the stakes are high: issues that shape your life prospects or decisions that are (substantially) irreversible. I guess Type 1 diabetes qualifies as such a case. Merely safeguarding someone's self-determination, the principle of empowerment, does not equal caring.[14] On the other hand, does safeguarding someone's well-being, even if this conflicts with what the person would want, equal patronizing?

Rather, I would say that is caring.

---

[13] I briefly point out a paradox here, which might throw some light on the risk of alternative 'holistic' approaches in medicine, as favoured by some strands in medical ethics and humanities. These strands promote a holistic approach giving weight to patient narrative as 'alternative rationality' (as Millness might presume it does). In contrast to that Dumoulin with his expertise and importance to medicine, could be (wrongly) classified on the side of 'logico-mathematical rationality', only concerned with scientific facts. One could ask that if medical care ends up with almost no science, what good narrative is on its own and how effective is the care offered?

[14] See Joffe et al 2003's empirical study on the growing importance patients give to trust and respect in the health carer- patient relationship, over the (over-emphasized) patient autonomy and shared decision making.

Moral philosopher Nel Noddings (1984) writes on the relationship between 'the one-caring' and 'the cared-for':
"We act not to achieve for ourselves a commendation but to protect or enhance the welfare of the cared-for. (...)We are sometimes thrown into conflict over what the cared-for wants and what we think would be best for him" (1984: 24).
She stresses the necessary *inequality* in this caring relationship as between a teacher and student, health carer and patient, as it is the nature of the cared-for's situation: the patient needs help. However this does not equal the traditional medical model of compliance, more is happening here than meets the eye: "The teacher (health carer) as one-caring needs to see from both her own perspective and that of the student in order to teach —in order to meet the needs of the student" (Ibid.: 66). Noddings calls holding this perspective of the other 'inclusion', which is a necessary attitude to be able to practice 'confirmation'. "I must see the cared-for as he is and as he might be —as he envisions his best self— in order to confirm him" (Ibid.: 67).

In an unequal caring relationship such as between a health carer and a patient (equally parent-child, teacher-student) the health carer needs to practice inclusion and confirmation.
"It is an attitude that both accepts and confirms. It does not 'accept' and shrug off. It accepts, embraces and leads upward. It questions, it responds, it sympathizes, it challenges, it delights" (Ibid.: 67).

One of the questions guiding this work is how to reach young people with diabetes, this challenging and difficult group. A step on the way is a question I raise throughout, whether these young people are as health carers say they are? And even if they are, is that it, are we 'realistic' and accept this reality as is? Though Nodding's last description of the care relationship gives the health carers' role almost biblical proportions —resurrection images: young people with diabetes levitating towards heaven— it rightly is more ambitious than "you just pray they get through adolescence without too much damage".

***

PART TWO

DOING DIABETES WITH AN INSULIN PUMP

In 1981, Dr. Pickup and his colleagues at Guy's Hospital Medical School in London, pioneers in the technique of CSII (Continuous Subcutaneous Insulin Injection), reported reactions of the first 15 diabetics after trying the 'portable syringe pump' for a period of three weeks.[1] Most patients felt their metabolic control was better with the pump, they also felt 'subjectively' better.[2] Mainly the greater flexibility of diet and insulin delivery rates was appreciated. The size of the pump was the major constraint against long-term use. Psychological reactions were notable: many patients reported that carrying a device that was noted by others made them more aware of being a diabetic. Also, relying on a mechanical device for the delivery of a life-supporting drug caused uneasiness. Some patients were thought of —or thought of themselves— as robots.

*

Insulin pumps, the initial topic of this research, have so far not figured in this text. Before portraying the young people with pumps, trying to understand how they deal with them, *do* them, I had to tell the other story, what went on before (and during) the pump entered the scene. The pump did not come into a void but rather in a firmly established scene and practices. These young people and health carers already have experiences with and ideas about diabetes and its management. As this specific context differed significantly from other places where diabetes is practiced and lived, it was even more pressing to portray it in detail.
Now we have seen the Millness approach to diabetes care and the contrasting Brussels philosophy, I can introduce, without further ado, this new type of insulin treatment into the Millness setting. Is the new treatment absorbed into the familiar scene, does it bring about any changes in care, health carer – patient relationships, diabetes management and results? I particularly focus on the changes the pump might bring to the young people: (how) do they incorporate the pump (and diabetes) into their lives?

Before focusing on the health carers and the young people, I present the other major player: the insulin pump.[3]

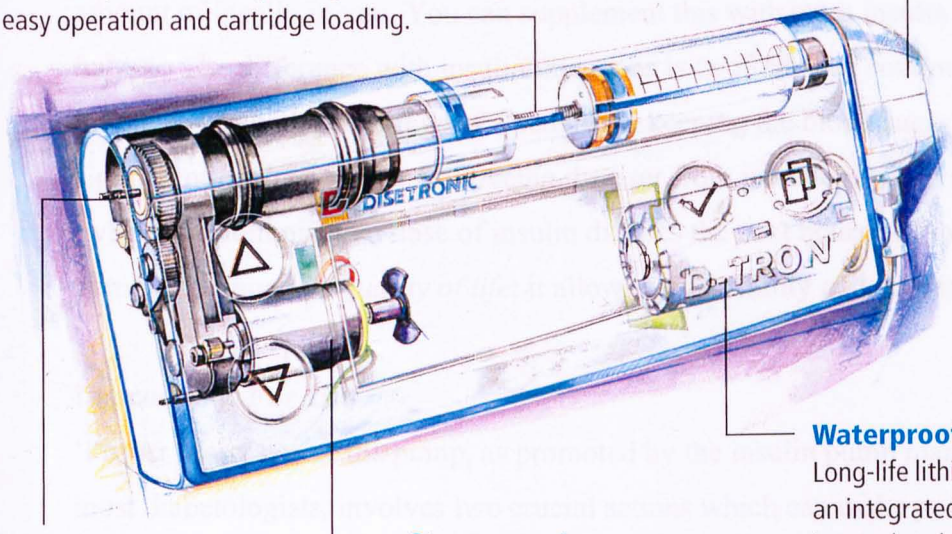
---

[1] Pickup 1981.
[2] The authors note that motivation was more important to a favourable response than occupation or intelligence.
[3] The drawing is taken from a leaflet advertising the Disetronic D-Tron insulin pump to possible new users. (Disetronic Medical Systems AG).

introducing groundbreaking technology

Cartridge adapter
Unique uni-directional membrane allows insulin to only flow out of the pump. Additionally, a rubber seal blocks debris such as water, dust and lint from entering the unit.

Piston rod with telescoping design
Hands-free operation, self-priming and rewinding for easy operation and cartridge loading.



actual size

Waterproof PowerPack
Long-life lithium power supply features an integrated membrane that balances internal and external pressure, while also ensuring a watertight seal.

Sensor
Innovative design detects occlusions and leakage at the cartridge.

Stepper motor
Whisper-quiet motor operation means no "clicking" and the delivery of exact doses in quantities as small as 0.005 units of insulin every 3 minutes.

The Insulin Pump

Outside: a small transparent plastic box, a LCD screen, + and - buttons to navigate through the menu, a S(elect) button to confirm. A long plastic tube leading from the box to a canula (tiny plastic tube) continuously inserted in the user's skin.
Inside: a vial with insulin, a rotating wheel to push up the insulin in the vial, batteries to operate the wheel and the computer.

The insulin pump is a fairly new method to administer insulin. This technological device is continuously worn on the body and every three minutes it pumps a small amount of insulin in you. You can supplement this with extra insulin at the push of a button. The difference with insulin injections is twofold. The continuous insulin flow imitates closely the workings of a pancreas: keeping the blood sugar levels stable has significant *health* benefits. By freeing the user from injections of set doses at set times (where the administered dose of insulin dictates the next hours of food and activity) the pump also improves *quality of life*: it allows for flexibility and spontaneity.

Instructions For Use

'Proper' daily use of the pump, as promoted by the insulin pump manufacturers and most diabetologists, involves two crucial actions which can make pump treatment hard work: 'bolusing' and 'testing'.

- *Bolusing*: taking insulin at times of food consumption (breakfast, lunch and dinner, and any snack time). The insulin taken through boluses ('bolus dose') is calculated at half the amount of a person's 24-hour insulin requirement. The other half ('basal dose') is provided automatically by the pump, in tiny doses every three minutes. One 'takes a bolus' by pushing buttons on the pump to give an instant insulin shot.
- *Testing*: to check whether the doses (basal and bolus) are appropriate, users should perform at least four blood tests, spread over the day, so they can adapt doses or interfere immediately with insulin.

What if these crucial actions are not performed?

- *Not bolusing* (forgetting or omitting): means that one does not get as much insulin as one needs. As half of all insulin is administered automatically, one does not physically feel if one has missed a bolus.

- *Not testing* (forgetting or omitting) has a similar consequence: it means one is not able to monitor blood sugar levels and act on them when necessary, in order to keep them more balanced. Another important reason for testing is to be able to spot whether the pump is malfunctioning (not injecting insulin). As there is no reserve of slow-acting insulin in the body, a malfunctioning pump could have catastrophic effects after a few hours, and can even be lethal.

> *"John was also the only one testing, that really frightened me, that those kids weren't testing and Dr. John said something I thought was quite funny. He said about the fact that they weren't testing: 'it's indicative of how much faith they have in pumps'. But David (the insulin pump manufacturer manager) was very worried and thought 'this can't be true this not testing' and I was frightened, but it didn't seem to worry Dr. John."*
>
> Mum of John (15), pump patient.

In the next seven chapters we first meet Callum, a cheerful adolescent 'on a pump' and then sit down next to William as he is introduced to his pump. Then follows a theoretical excursion (Chapter 6) to situate the following ethnography in the (anthropological) literature on technology and mind-body and other dualisms. After which we return to the ethnography in Chapter 7 to observe the Millness health carers' approach to pump therapy, with pump nurse Sheila as protagonist. Chapter 8 considers how young people wear and *do* their insulin pump. Chapter 9 briefly describes how other health care teams (in Boston and Gothenburg) *do* insulin pumps differently. In Chapter 10 we interpret these different ways of *doing* diabetes, compare them with the Millness approach and look for some explanations for variations in both care approach and outcome. In Closing Remarks I restate the major points of this study.

*

Callum

A Young Person With an Insulin Pump

The first time I meet Callum is at the local cinema-art centre. Dr. Veronica, a young paediatrician at the diabetes centre, has invited 15 young people with diabetes to share their views on a new diabetes website about to be launched. Two young people show up. Callum is one of them. Callum is a mature teenager, 15, teenage skin, chubby, cheerful and chatty. He seems relaxed, happy to be here and to be of help. I know Veronica had hoped Callum would come, as "he is a bright boy who is so much into technology and computers". I also know Callum is 'on a pump'. Sheila, the pump nurse, going over her list with young people on pumps, described Callum as a boy who "piles on the beef. With the pump he started to eat and put in insulin. He was skipping insulin before the pump; maybe he forgot his insulin before the pump, now he doesn't. He gained a lot of weight." The words 'piles on the beef' will stay with Callum and I always imagine him with steaks tied around his waist. So this is Callum, who is into computers, wears a pump and piles on the beef. I tell him who I am and ask whether I could come and talk to him sometime about his pump. No problem. Callum says he likes his pump and doesn't mind talking about it.

After the meeting we happen to queue for the same bus home. I tell him how anthropologists normally, when they are abroad, tend to live for some time with people so they can see what they do in everyday life and try to understand how they live. Since I try to understand how teenagers live with diabetes and pumps, that would mean, actually, that I'd have to stay with them for a few days. To see what their everyday lives are like. Callum replies: "Yes in Africa, but here nothing happens; we don't *do* anything. My life is just like anyone else's, there'd be nothing to see." During the ride home we arrange that I come to see him the next week; he gives me his mobile number, his phone number (he has a private line) and the phone number of the house. As he gets off the bus he puts his sleek headphones on, starts his minidisk and walks off into the night.

A week later, I cycle into his street, two rows of council houses. Callum is looking out of his window. He lets me in. The house, a ground floor flat (two bedrooms, a living room and kitchen) is tiny and packed. Things are everywhere: on tables, sofas and mainly on the floor. Callum lives here with his mum, an old people's nurse. He seems to spend a lot of time on his own, either on his computer or watching television, and seems fine with that. We go into his room, the cat follows. His bedroom has a bed and desk, pride of place is taken by large electronic piano keyboards, in front of the window. A second desk with a computer and printer, an impressive stereo, a large television, playing, a complex looking phone with screen and I guess fax, another stand alone phone. When I ask about two phones in one room, he shows me his mobile phone that is broken at the moment: "I probably cracked it because it is so small". The mobile is metallic orange and indeed so small it looks like a chocolate miniature, in silver wrapping. Callum hands it to me saying it's even lighter than his pump, and smaller. I reply he doesn't have to be embarrassed about this one.[1] He smiles. Apart from the abundant mess (clothes lying around, papers, coke cans) Callum's room looks like an office. It is very connected. He is the master conductor. During my visit he taps on the keyboard to go to internet sites, to show me which new pump model he is talking about, or to convert the dollar price into pounds, he deletes a few messages from his mailbox, turns off the television (remote) and switches on the stereo, adjusts the volume (different remote), all from his swivel desk chair. I sit on his bed and ask questions. His room, with the wiring, electronic equipment, noises and beeps makes me jumpy; as I am focussed on the pump I haven't yet seen and am waiting to notice. As we talk, something starts to beep. Though the sound comes from the wrong direction, I ask whether it is his pump. Callum replies it's the clock. "My pump beeped a while ago. The cartridge is almost empty."

Griet [*concerned, thinking if the pumps beeps to tell you the insulin cartridge is almost empty, you better act on it*]: "Did you fill it?"

Callum [*relaxed*]: "No, in a while, I wait, there's still some in it."

[1] I am referring to current TV commercials of three different phone companies on the theme of old mobile models being an embarrassment to their owner, so go and buy a new one. Slogans include: " Life contains enough embarrassments without your mobile phone having to be one" and "Ashamed to be seen with your mobile?". The ad ends with the image of a mobile with a paper bag over it, weeping, abandoned by its owner.

At the end of our meeting, Callum surfs to the website of Minimed, an insulin pump company. We study their newest model, it costs $4500. Callum says it looks smaller and definitely must 'do' more things. Callum tells me he likes the Minimed pump (his is a Disetronic one).[2] I ask why? He leafs through his diabetes magazines to find the advertisement where he saw the picture. He doesn't find it. He surfs to the Minimed UK website. There it is. "It looks smaller and it has a key ring". I am nonplussed, a key ring on an insulin pump seems a unnecessary gadget to me. What else will they invent? Callum explains: "Yes, you see: you can do everything from there." Is the smaller the better? "Yes, and it might do more." Would you buy a pump yourself? "If I could I would buy a new one, 'cause it's very good." He tells me he would like to see the pictures of different pumps and what they do if he was going to buy one himself. We could be Internet shopping for a mobile phone. The same fashion categories seem to apply: as small as possible, a trendy look, and it should 'do' a lot. Callum has surfed on: "This is another thing I would like" we are looking at a picture of a Glucowatch (a continuous blood sugar meter). Why, because it means no finger pricks or offers continuous reading? "No pricks, and yes, also continuous reading." —Callum always asserts that finger pricks don't bother him at all.

Over our next meetings and conversations, Callum will be the relaxed boy, in charge of his equipment, screens and buttons, constantly fiddling with it while talking. Master of the electronic world. I will be the technology-wary older person, not understanding how all these things work. I take my usual place on his bed, he sits confidently in his executive chair, all remotes and keyboards in reach. Callum lives with his mum, his dad left when he was one. His dad lives close by and Callum often goes to see him. His mum is a nurse who goes to old people's homes to help during the day. She has to work hard to earn a living. Callum has decided he wants to get on in life, he sees computers as the future, he wants to become an expert on them, get a job, work hard and fast, make lots of money and enjoy a long and early retirement. Whereas this may seem 'adolescent' bragging, I find Callum very mature. He has seen and lived trouble, him and his mum struggling money-wise. He has used some of his inheritance money from his granddad to buy his own computer. He spends his days surfing the web and hanging around with his few good friends. He says he is not into typical teenager stuff like other

[2] Disetronic and Minimed are two of the major companies manufacturing insulin pumps.

boys at his school, causing trouble, hanging out on the beach in the evenings and getting drunk. Callum seems very confident among adults. The doctors and nurses of the Millness diabetes team call him "a great lad", "he sorts himself out". Talking to him is fun, he is quick and jokes around; when I tease him he is fast to pick up on it. In company, he is generous and cheerful. Of course, he's not always like that. His mum had a hard time with him last year; he didn't talk to her at all, always being grumpy. "He's a good boy, but he is having horrible moods and I just don't know what to do with him."

*

Callum was diagnosed with diabetes six years ago at the age of 9. He remembers it was Burns Night, he was really ill and he had to be taken to Millness hospital in an ambulance. He woke up the next morning in hospital and felt horrible, he was told he had diabetes and he didn't know what it was. The diabetes nurse explained. He claims that having diabetes didn't affect him much, "it just took a bit of getting used to". "I do not see it that I can't do things, apart from driving buses and stuff." His mum says that after he was diagnosed he came to her and said "oh, I'll never be able to go abroad"; she told him that wasn't true and she made a point of it and took him to America. He also lamented to her he would never be a jet fighter pilot. When she replied she didn't think he would have become one, even without diabetes, he had to agree. Having diabetes does not seem to impede Callum from doing anything, she says, and she has tried to not hold him back from anything.

From the first day of diagnosis, Callum has been the one in charge of his diabetes. When I ask maybe also, a bit, his mum, he reacts strongly: "Oh no, I don't trust her. I would never trust her to give my injections and she's a nurse. She's like 'the Scary nurse'." I quiz him twice, saying he must be joking, is he being ironic? He repeats he is serious, he wouldn't trust her. Mum gives a similar account: "I remember when we were at the hospital and he was taken of the drip and the nurse was going to give him his first injection; knowing I was a nurse she asked if maybe he'd rather have me do it and he said 'No fear!' I'm not letting her near me' and he did it himself, just like that. They were quite amazed at him."

The first years Callum took his diabetes management very seriously. I hear from his mum that there was a time he was obsessive about his blood controls, and both she

and the diabetes team told him to lighten up a bit. Callum's blood sugar levels have been stable and his control is very good. He is very informed about diabetes, keeps reading up on it and his mum has told him about it and about possible complications later. While being very aware and informed, he is also very relaxed about it. The only thing his mum worries about is, as she calls it, his 'overeating': he eats both the wrong things and too much. Callum indeed eats lots, says he eats what he wants and has never limited himself for his diabetes, over time he just learned to get a balance (to cover his food intake with the right amount of insulin). We are talking serious quantities. One day as I enter his room, a construction of 12 boxes of 12 golden Diet Caffeine-free Coke cans each and a 24 pack of Diet Irn Bru forms a crafty table in the middle of the room. Is he having a party? No, this is just what he drinks, on a strong day he'll get through one box (12 cans). Callum explains he gets very bored, sits at his computer a lot and eats all the time.

Well informed about diabetes, Callum says he learned most from diabetes magazines for young people [3] that "just come in through the door, probably my mum pays for them".[4] He mainly looks at the advertising in them, to see whether there is some new equipment (meters, pumps) and he'll read the "scienty bits" when they seem interesting. This is also how come, he says, he is now wearing a pump. He saw the pump advertised in a magazine and asked the diabetes clinic about it, "years ago"; he asked again, they said they might get some "and when they got some last year they asked 'would you have one' and I said 'yes'". His mum says the clinic proposed the pump to him because they knew he'd be motivated, as he's always doing things with technology and computers and reading on new development. "He likes gadgets so the pump is ideal for him."

The pump does seem to suit him very well, and I am surprised at how relaxed he is about it.[5] Last summer he was on holiday in Greece for five days and the first day the pump stopped working. He had not, against all advice, taken any insulin pens with him in case of such emergencies, he only had some Novorapid (fast acting insulin). So he just held the tube and gave the insulin himself, by tapping on the cartridge "I just

---

[3] *Balance* (young people's magazine of Diabetes UK), *Diabetes UK* (general Diabetes UK magazine) and *Countdown* (American young people magazine).

[4] He mentions this in reply to my question whether he subscribes for these, how does he get them? His mum will tell me she finds it very important he is educated about diabetes and so she subscribes to two young people diabetes magazines for him. "He usually takes them with him when he goes to the loo: Diabetes UK and his mobile phone and his portable phone, and sometimes he can even be talking to both at the same time."

guessed how much I was giving". [*I am baffled; a year's research in diabetes has taught me that if there is one thing important about managing diabetes, it is administering the correct dose of insulin.*] Did he know why it stopped working? "I think it got water in it." "You mean, you wore it while swimming?" "Yeah, it must have been cracked, it should be water locked." [*I remember the bib-like contraptions Sheila gets out when she reaches the topic: what to do when taking a shower.*] "But, don't you wear a plastic bag over it, like when you shower?" "No, I just put a cap on the battery, that should be watertight. But at Corfu I opened it and inside it was rusty, so it must have gotten water in. So I cleaned it out and put it out in the sun to dry, and the last day it started working again." I check: "So you actually broke a pump?"[6] "Yes, but I got a replacement." "But what did they say, weren't they annoyed?" "No, at the next clinic I'll take it and they'll send it to the company. I'm sure they are insured." His casualness is distressing. "So you broke a pump of £2000?" "1000, they come in twos, one is a replacement in case the first comes wrong and a pack of two is £2000".

"But now with the pump..."

"So I told him, I said 'we have to make economies' and I said 'Callum we're going to get rid of'... and I was going to say 'his separate phone line', but his face was stricken [Callum's mum pulls her hand down over her face] and he went quiet and pale and he said: 'the pump?' and I said: 'no kid, I would never take away the pump'."

At our first conversation when I ask Callum what diabetes means to him, both practically and as to who he is, his answers quickly switch to: "but now with the pump...". He seems to divide his life with diabetes (six years) in "before the pump" (five years) and "now with the pump" (one year).

---

[5] After all, this *is* a life supporting and (in case of malfunctioning) a possibly lethal technological device.

[6] My amazement at his matter-of-fact ness is mainly because he has been given this pump to use for free. Normally he would have had to buy it himself for £1000, but he is (according to me and himself) privileged that he is selected for this pilot project where only ten young people in Scotland get the chance to try a pump for a year. It seems a strange attitude to me to be so casual about breaking expensive equipment that isn't your own, by carelessness or laziness, and not feel uncomfortable about it.

> I ask what diabetes means he has to do, he replies: "I have to remember to inject, do blood sugars, remember to eat something, but now with the pump..."
>
> He tells me his 'goody two shoes' friend Ben takes care of him: "We go back a long way. He tells me when to eat sugar, goes and gets it for me, 'have some sugar' ... 'naaaahhhh' ... 'come on, have sugar'. But now with the pump..."
>
> "Like before the pump, I went out with friends in Millness and at night I had to go home because I had forgotten my pens."

With the pump, Callum is more 'in charge' of his diabetes. He decides what insulin he needs and administers it. Several times a day he reacts to his diabetes, both when he eats or when he feels bad (high or low) he will address this with insulin. He is a 24-hour autonomous caretaker of his diabetes. The five years he was on injections, he would perform routines drawn up by the diabetes health carer. "Before I got the pump I wasn't happy changing the amount of insulin, like I didn't want to touch it. Every time I went to clinic the doctor said 'well, what are you on' and they would look at my blood sugar diary. He would say 'ah, a bit high here, we'll increase that, they're a bit low here, we'll put that down a bit'. (...) I probably could have changed it around myself, but I just didn't want to like, tamper with it." I ask him why on the pump he does change it, what is the difference? "With the pump, you just put so much in at breakfast time, so much at night, it's just flexible." I reply that it seems that he is more on top of his diabetes now, it's more like *his* diabetes, not someone else who decides the dose? "Yes, you control it."

The fact that Callum is relaxed about other people knowing he has diabetes, is significant to his positive relationship with the pump. The pump can make diabetes visible and present 24 hours a day. Others can see the pump and ask what it is. Diabetes becomes public. Callum's diabetes has always been public. He is not ashamed he has it nor does he mind people knowing he has it: "I've got it, I have to live with it, it's not gonna go away. It doesn't have a big impact on my life". "Would you call yourself a diabetic?" Callum: "Yes, I have diabetes", but it is not a big part of his identity "It's just me and there's diabetes on the side". Callum makes sure people around him, friends, schoolteachers, know he has diabetes, so they are aware in case something happens to

him. If anything, the pump has made this public perception of diabetes easier. It has normalized Callum's diabetes in a way, and fits it into his teenager attire and behaviour. The pump has made giving insulin for Callum almost invisible. "Sometimes I've known people for weeks and then I'd say 'I just have to give my insulin' and they'd go 'Oh you have diabetes, I didn't know'." When he was on injections, it could be awkward when he was in a restaurant and many people were watching. He was not embarrassed "I just say 'I have diabetes, what's the big deal?', but people have given me some very dirty looks sometimes, or about to call the police, because they thought I was taking drugs." Now, when he wore the pump on his belt —which he stopped because it kept falling off, it now lives in his pocket— even though people see it "they don't care, and I'm a teenager, they'll probably think it's my music".

How did his friends react to the pump, did he show it to them? In his deadpan way Callum replies: "I said: here's a pump. It's cool". Did they think it was interesting? "My friends are boring." Do people ask him what it is, when they see the pump? Callum says that people don't care and that he can't be bothered to explain it, he has done it so many times. "Everybody says: 'what's that then?'" he sighs loudly. As he advises a boy who is keen to go on a pump, but anxious about friends at school reacting strangely and pestering him: "They'll be OK about it, they don't care, and otherwise, you just fob it off, you say 'ahhh, you wouldn't understand'".

Callum's pump has become second nature to him, he is at ease with it, he knows what it does. He trusts it and uses it as he wishes. This is significant, as other people can feel very uncomfortable about machines and technology, especially when attached to their body. Not so Callum, the pump is a device for him, like his minidisk, his mobile phone. These are things that are at his disposition and that he controls. When on several occasions Callum explains to me how to work the pump, he is so fast —how do you explain something you don't really think about any more, like riding a bike?— I always get lost half-way. A conversation would go like this:

Griet: "The pump says 'Error 5', what does that mean?"

Callum: "It means 'maximum bolus achieved'. I think you have to put over a 100 in bolus in or something because you can't put in 25 units at a time. One day I just sat there seeing how high it would go, so you can put 25 in and it won't go."

Griet: "And then you can cancel it?"

[Callum pushes the buttons to give instructions to the pump; we hear the beeps.]

Callum: "If you leave it to put that in, it gives you 8 seconds, then it will start confirming it."

Griet: "You don't have to confirm it?"

Callum: "Right, for it to stop, you just push the top buttons. So either if you put too much or too little in, you want to cancel, just press. You push three buttons at the same time for resetting it, so you put a new cartridge in and then press the top two buttons."

At this point I am lost and ask Callum whether he read the whole instruction book that comes with the pump, to find out how it works. He laughs derisively: "No. You just press the buttons and see what happens. 'Cause you can always stop it." Does he then just go to the Menu on the screen? "Yeah, I mean, it's pretty simple, there's only eight things... and that one there [*he points to an icon that appeared on the screen*] is the one for priming in, that one here [*he has made another icon appear*] will only work when it's off, when it is in stop mode, you can turn it on and off by pressing the two top buttons together."

As I leave, his mum mentions how Callum is "so much happier with the pump. He has said to me it has made such a difference to his life, that he doesn't have to be regimented about his life, he just does beep-beep-beep."

*

William Gets His Pump

Today is 'pump day' for William. Last month William (15) a bright and articulate, sinewy boy came with his mum to see Dr. John in clinic. They enquired whether he could try a pump. Though mum was prepared to pay for one, they were in luck: a patient had just quit wearing the pump and moved back to injections. William can get this pump. They arrange for Sheila, the pump nurse, to come to his house to install him on the pump. Sheila and I drive to his house, on a sunny school-day afternoon. William's dad has taken time off work. He tells us he wants to be there to understand the pump, so he'll be able to help Willy if something happens.[1] We sit around the kitchen table — mum, William, dad, Sheila and I— for two and a half hours, in deep concentration. Sheila asks William whether he has seen the video, and we all laugh at the exaggerated American scenario of the impatient patient, asking her doctor to explain the pump. Sheila places a blue plastic suitcase holding the pump and all its accessories on the table. She takes out the pump. A small transparent plastic square box, flat, the size of a pager, with two buttons on top and a LCD screen on the front, with more buttons on either side. During her 'presentation', she will address William and teach him how to set up his pump and operate it. William will hold the pump; push the buttons enthusiastically, occasionally skipping a selection, going too far and having to retrace his steps to get back to the correct point, intensely looking at the screen to see what happens and which numbers show up. For anyone who didn't know, he would just happily be playing a videogame.

Sheila: "First, you put in the batteries. What do you remember?"

William: "Just the black seal..."

[1] Unlike Charlie or Callum, William is not a 'standard' patient. Both William's parents have a university education, the family moved into the UK only two years ago, they are familiar with the Canadian health system. They are, without being overbearing, concerned about their son and involved in his diabetes. His mum was prepared to pay for the pump, his dad took time off work to be at the pump induction. While all 'atypical' characteristics (for Millness families), I portray William's induction here, as it is the only lengthy one I had the chance to observe.

Sheila: "Here are the blue batteries, they're a bit iffy, the error code can come up on the pump, so make sure you have some spare batteries… first you put in number three…"

[*William puts the batteries in, and closes the rubber seal*]: "is that to make it waterproof?"

Dad: "Is there a warning, for when the batteries stop working?"

Sheila: "There are audible tones, which you can't switch off. The next thing is to put on the clock; it's a 24-hour clock, a military clock. Next, you press the S (Select) button, press down to 'clock' and then put in the time… There's an 8 second delay: just press the button and it comes off…"

William: "Oops, too far"

Sheila: "That's normal, don't worry about it."

[*William puts in the time, with + and – buttons*]: "25 past 2".

Dad: "Make sure it's military time."

Sheila: "Right, that's the pump up and running. On the bottom it says 3.15, that is the amount of insulin in a full cartridge. Now we'll fill up the syringe with insulin. Wash your hands first, this is all sterile. You can draw up 3 cartridges out of one bottle and put them in the fridge."

[*Sheila takes a syringe out of its plastic cover*]: "This needle is purely for drawing up insulin, I tell you."

William [*frowning*]: "I hope so."

[*William takes the cap of the needle*] "OK" [*and sticks the syringe in the insulin bottle.*]

[*Sheila turns the bottle upside down*]: "this is how it works"

[*William fills the syringe, pulls the end back*]: "whereto? It's got an air bubble at the end."

Sheila: "Tap it with a pen."

Mum and Dad: "Flick it with a finger."

The four of us watch William flicking his syringe, full concentration. Sheila, an experienced nurse, gets rid of the air bubbles and fills the syringe up till the end.

Dad: "Do you know why you're not supposed to have air in it Willy?"

William: "I don't think it's good to have air in my blood."

Sheila: "It's not so much air in your blood, but the pump delivers only a tiny bit of insulin every three minutes, so if that is just air…"

Sheila: "Now take this thing off [*she twists off the needle part*] and put on the cap, that's the cartridge. Now, we want to put the insulin in the pump. The screen tells us it has 3.15, but when it changes" [*Sheila takes the instruction book that comes with the pump*] "you have to reset this, as you replace the cartridge. Press the S button twice and then the H and M simultaneously. You should now see the program. You need to do that every time you change the cartridge."

William: "It turned itself off again."

William continuously holds the pump with two hands, and when he does put it down, he immediately picks it up again to look at it.

Sheila: "Now we're going to set your insulin, how much are you on now?"

William: "Mmmm..."

Dad: "Get your book out Willy."

Sheila: "50% of your total dose will be the basal rate, the other 50% is the bolus.[2]". [*Sheila takes out a slide rule and explains the glucose amount.*] "And probably you haven't noticed you are not feeling as good as you could."

William: "Not really."

Dad: "Probably we have noticed it more than him."

Sheila: "William, if you put the sliding rule on 25 that should tell us what to do, you write it down: 4 to 5 a.m.: 1.6; 5 to 6 a.m.: 1.7."

William fills in his hourly basal rate sheet with the insulin dose he needs every specific hour of the 24-hour clock.

Sheila: "Now, we're gonna program that into the pump, press the S button again and scroll down till you're at P."

William: "Gotcha."

Sheila: "Then we will see, what does it say?"

William: "Program lock 38.4."

From this moment on, Mum, Dad and I are lost. This is a coded conversation between Sheila and William.

---

[2] Bolus: instant dose of insulin, which is given at mealtimes or when eating a snack, to cover the sugar intake. A bolus is additional to the basal rate, which is automatically delivered every three minutes.

Sheila: "Press three buttons together, what you will find is 00:01, so press the S button again, you get 00:01 and fill in 0.7, then press the S button again, you see 01:02, put in 0.8."

William puts in his hourly basal rate, the basal amount of insulin the pump will deliver him every three minutes, and this can be specified for every hour of the day.

Sheila tells him which amount to program; William pushes the buttons, repeats the number and beeps along.

William: "2.1 " [*beep beep*] "there we go. 1.1, yeah" [*beep beep*] "4 to 5? Damn, I'm on 5 to 6."

Sheila: "OK" [*she waits*].

[*William goes back to the start of his programming dose and checks out loud*]: "1 to 2: 1.5, 2 to 3: 1.8."

Sheila confirms. William finds a mistake at 13 to 14 and corrects it.

William: "16 to 17: 1.5, woops, 1.5, here we are."

They conclude the 24-hour doses.

Mum, Dad and I look at each other, Dad lifts his eyebrows: "computers".

Sheila: "Now it should give you a total at the bottom."

William: "27.4, should I lock it?"

Sheila: "Yes, do you remember how to?"

William: "Yeah."

Sheila: "Now we need to put the cartridge in; as the pump delivers insulin, this little blue wheel goes up, so when there is a new cartridge in, wind it back to the beginning."

William winds the blue wheel back, holds on to the top and clicks it in place, puts it in the pump, puts the cap on.

Sheila: "Fine, you got the cartridge in and we programmed our basal rate"

Dad: "So you can check at any time how much is in there?"

Sheila: "Yes. The next thing to do is the canula."

William holds his head in his hands. This is the moment he has been dreading from the start.[3] He does not like needles. One of the reasons he is so excited about the pump, is

[3] This is the high/low point of all pump introductions. All young people are excited about the pump and how it might change their lives, but the sword of Damocles hanging above each induction is the fact that at some point in those three hours of new gimmicks and tools, they will have to put this canula, a needle with a plastic tube, in their belly. Once that point is over and they successfully inserted the canula, ready

that it means less needle pricks in your body (only one every three days, when the canula is replaced).

Sheila: "I think we'll try the long canula first, it goes in your tummy, you'll be fine."

William clasps his hands.

Sheila: "So what do you want to do first? The canula in or finish setting up the pump? And Griet has kindly offered to put in a canula too, to give you support."

William: "The pump."

William puts the tube, through which the insulin will be delivered, on the pump.

Sheila: "Screw it on tightly. This is important, otherwise the pump can leak. This is the bit that attaches to the canula. Now we need to prime the pump, do you remember?"

William: "Is that making the insulin travel through the tube so it is ready to come out at the canula?"

Sheila: "Yes."

The pump zooms and we watch the insulin travel through the tube.

[*William watches closely, intrigued, he follows the insulin through the tube*]: " I can see the reason for the short one (tube). Shall I stop it?"

Sheila: "Press three buttons and it will keep on priming."

The pump is ready. We cannot put it off any longer; the moment has come to put in the canula.[4] William and I are washing our hands in the sink. I ask if he is nervous. He is, I say I am too. I tell him that other boys usually are sweating when they have reached this point in the introduction, he is doing really well. I take the canula and put the needle slowly in my stomach. All watch. Mum and Dad joke whether I want a piece of chocolate or a biscuit because I have been so brave. William puts in his canula, slowly. We all cheer and congratulate him, he looks a bit pale.

William: "I have a shower every morning, do I take it off?"

Sheila shows him plastic bags to cover the pump in the shower.

Mum: "Maybe the canula should be a bit lower down, below the belt?"

---

now for the pump to be linked to them, the air clears up. —Though some youngsters spend the rest of the induction flat on the floor, feet up, to remedy the low blood sugar brought on by the fear of the procedure.

[4] The device to insert the tube in the belly, it looks like a small plaster with a needle in it, the needle has to be put parallel in the skin of the belly, then the needle is pulled out, leaving a small plastic tube, through

William shouts: "I am not changing it!"

Sheila: "It is the same principle as with injections, not always on the same spot, keep changing sites."

William [*eager to complete the process, now the dreaded part is over*]: " OK, I'm ready for the pump."

Sheila: "See, this end of the tube, it just clips in."

William announces proudly: "Now I am *connected.*"

Sheila: "First press the S button and hold it: you'll have a beep and three short ones."

Mum: "You were saying there are various ways of carrying these."

Dad: "Have you thought where you're gonna put it Willy?"

Dad: "It won't be visible either, if lower, under your trunks. That's what you need to think about. How much play is in that tube? What if it gets yanked? I'm just thinking of the baboons at school."

Sheila: "Just check it. It would be difficult to disconnect it at the top."

William: "One major question I have is about the bolus, say, if I have a chocolate bar, how much insulin would I give myself?"

Sheila: "Right. We go back to carbohydrate counting, as in olden times, but now it's more flexible. You have to talk to Mandy (dietician) about that. What would you normally have for breakfast?"

(...)

While Sheila explains the insulin rates and Mum and Dad listen and take notes, William takes the pump out of his pocket, out of its leather purse and looks at it again, holds it, this new toy.

Dad summarizes: "So, if I understand correctly, we programmed in 50% basal rate, is the other 50% the boluses, should that more or less come to the same?"

Sheila: "Yes, and it does. But these are flexible and they can change, but I'll put it down."

Again William takes the pump out of his pocket, fiddles it around; he looks at all the different bits that come with the pump, in the blue suitcase. He fishes out a thin bit of plastic: "Is this a bandage?"

Sheila: "Yes."

---

which the insulin finds its way in the body. Every three days this canula has to be replaced to prevent infection.

William [*in his own world, takes out his pump; it beeps*]: "So it should be in 'run' mode? It says '1.4', is that what I'm getting now? It doesn't make any noise, does it work? How do I know if it still works?"

Sheila: "Check if you feel bad, 'cause you have fast acting insulin. So keep in mind it is a piece of kit. Now, one crucial thing I must tell you, every 12 hours you have to press a button, or it automatically goes in 'stop' mode 'cause it thinks you might be hypo. If it is beeping: it either is in 'stop' mode or it might be low batteries. Use your book the first time to do things, right?"

Mum: "Even if you think you remember Will, do the booklet."

Dad: "I expect, for the first few times, Willy might have some company when he'll be doing it."

William, occupied with the pump and its novelty, is oblivious to the practical guidelines conversation: "The tube doesn't bother me, I think it's a good length."

Sheila pulls him back to the topic: "If you don't put it in 'run' mode, it will bleep."

Sheila takes the booklet that explains how to operate the pump: "So, as it says: temporary basal rate, I'm not going to go through it, it is quite straightforward. So for bolus tonight, we try 6 units. You can do this in 'run' mode."

Dad: "So you don't have to interrupt things?"

Sheila: " No. Now, if it's more than 4, do 3 at the beginning of tea and 3 at the end. By pressing the H button you put in the amount of insulin you need, then you wait 8 seconds, and then you hear a series of beeps to confirm. It's all written there. If you follow the book, it's easy."

Mum and Dad [*a bit weary*]: "Yes, it's just at the beginning…" [*to William, fidgeting with the buttons and beeping enthusiastically*]: "You can't wait to do that?"

William: "I'm just sort of figuring it out, I'm having a look."

Mum: "Will hypos still be possible? For example, if he forgets to take his bolus, he will feel that?"

Sheila: "Yes, blood sugars will go low."

Mum: "And his aim is really for low blood sugars?"

Sheila: "Yes, under 10; between 6 and 10."

Mum: "OK."

Sheila: "We'll keep an eye on how things are going."

Sheila is getting ready to leave, William is engrossed in his pump and extras, a box full of goodies to play 'nurse': syringes, plasters, bits and pieces to replace and attach to the pump or body, all sterile packed in plastic, extra boxes.

We watch him.

Sheila: "Are you quite happy then?"

William is busy closing the newly filled cartridge "uhoh, there's no click."

Sheila: "Ok, I'll ring you tonight."

William: "Is this box mine to keep?"

Sheila: "Yes"

William: "Gotcha."

Mum: "He should notice his bolus right? And write that down."

William [*with us again*]: "Where?"

Sheila: "In your book."

Mum: "And you have to figure out how you're gonna sleep with that."

Sheila: "Another thing, carry a little card with you, saying you're on a pump, in case something happens."

William is busy organising his box. He takes everything out, then puts everything in again and tries to fit things in the most appropriate places.

Sheila turns to William. We watch him being meticulous about his newly acquired accessories, he is unaware.

Sheila: "Is your bedroom this tidy?"

Mum: "His computer stuff, he keeps that tidy like this."

In the car back I tell Sheila how excited and eager William seemed about his pump. Sheila agrees and says that at the end, he wasn't paying any attention any more; he wasn't listening. "He'll mess up, because he won't read the book, but it won't work, and he'll have to go back to the book and read it."

Two months later

Sheila and I have just paid a follow-up visit to check how William is getting on. Mum is delighted about the pump, as are Dad and William. William looks better, has put on

weight, feels better, is less grumpy. The pump is no doubt a big success. In the space of two months, it has improved William's and his family's lives. He feels a different person. And all this by dabbling along with it on his own, without too many guidelines or "this is what you have to do". Rather, by trial and error.
In the car back home, Sheila comments: "Ketones. When the pump comes off he has to check for ketones, when it has been off for five hours and he hasn't been getting insulin he can go into major ketoacidosis. He doesn't realize he is only on short acting insulin now and that he does not have anything working in the background."

Sheila has just provided me with a simple explanation that convinces me of the importance of testing for ketones.[5] It is straightforward: if the pump comes off, especially at night and you don't know how long it has been off: check for ketones in urine. Yet William "does not realize", as Sheila said.

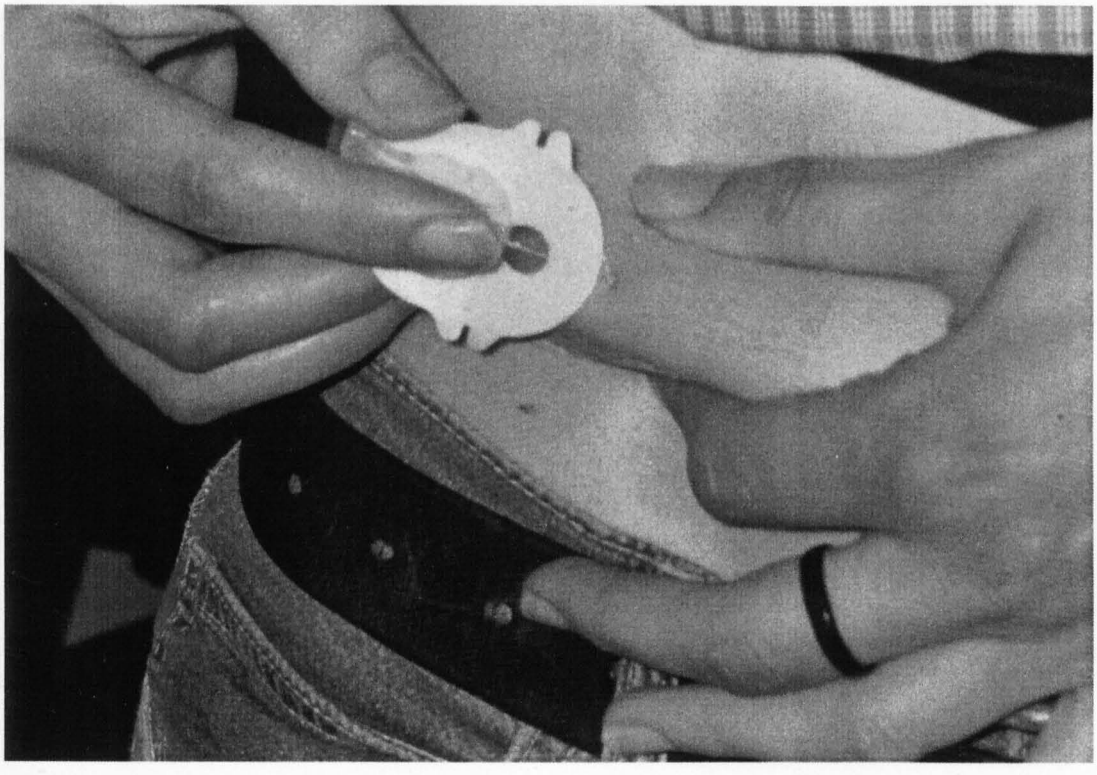
Why does she not *make* him listen, and make him realize?

*

[5] Ketones (see also Glossary): produced by the body as it breaks down fats for energy. In severe cases this process may lead to coma and death.

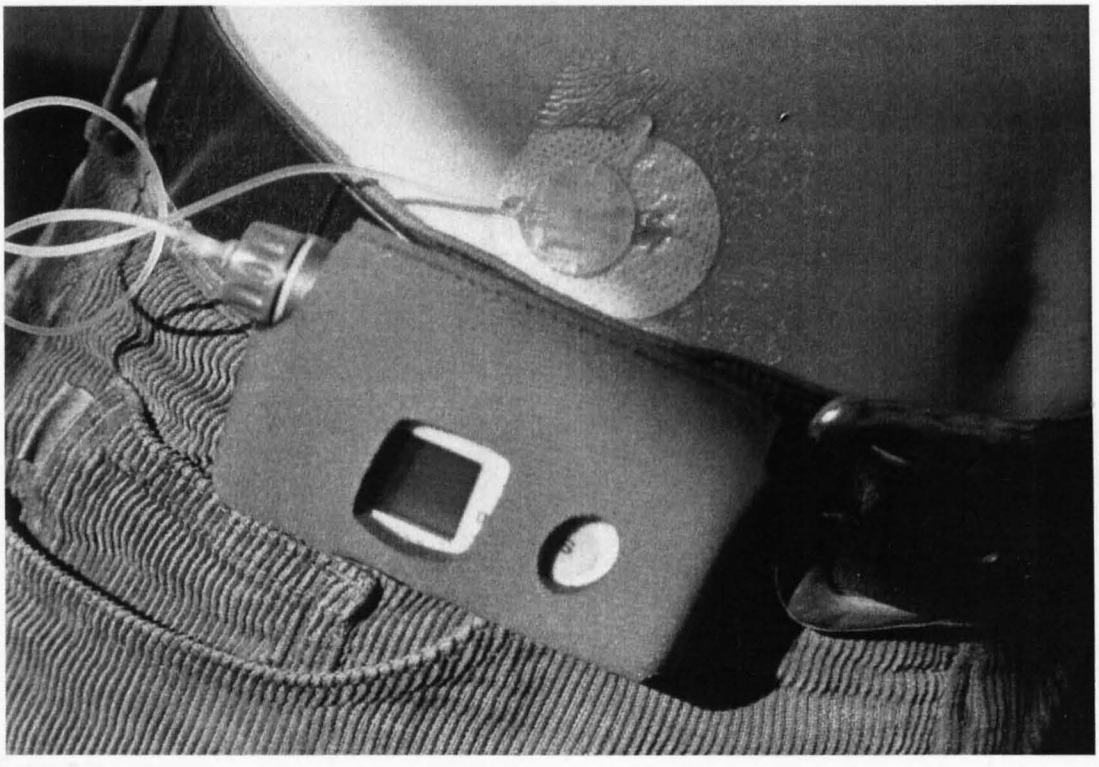
P - Day in Millness Paediatric Clinic

A well-stocked table: getting ready to attach the pump



Inserting the canula

The pump is attached, ready for use



The pump in its bright red 'scubadiving wetsuit'

Ready to go

6

People and Technology

The Literature

How to relate to the literature? It feels artificial to separate literature and theory from the ethnography, as there was and is an active two-way traffic between them. A theoretical standpoint coloured my focus in fieldwork and the ethnography in its turn led to literature and theories to help with analysis. Here I relate this process of reading, looking, and finding: an existential dynamics of the research.[1]

This text is about technology. Better, it is about *people* and technology. 'People' are the crucial point, not only in the ethnography but also in relating to the literature: how to safeguard the 'person' when talking about technology?

To Arturo Escobar's call for an anthropology of cyber culture, Marilyn Strathern remarks that there was never any pre-cyber culture (Escobar 1994: 226). Technology and cyborgs do not call for a new type of anthropology. Whilst welcoming Escobar's plea for an 'anthropologisation of complexity', Strathern warns against taking complexity as if on a spectrum, at the opposite end to 'simple'. She locates complexity "not in its effects (how the world appears) but in the instrument that produces that effect (human perception)", and thus, instead of being a matter of scale, complexity is a matter of (perception of) detail.

> "*Technology makes explicit the nature of the lived world precisely in terms of the concrete (technology works) and the heterogeneous (it brings together different orders of knowledge, mixes of material and personnel, and so forth).*

[1] As mentioned in the Introduction, relating to the literature through my own search and questions is not to centre on myself, rather to show that it is *not* me: these are theories, ideas, ways of thinking about the world that I distinctively consider. At the same time it avoids giving the impression of factuality, making instead explicit the fluidity: trying out ideas.

> *(...) Now that we see hybrids everywhere, it was probably inevitable to see hybridisation as a higher-order fusing of technology and culture as such*" (Strathern in Escobar 1994: 226).

Strathern remarks that there is nothing post-human about hybrids, she points to "the cyborgs persons everywhere already make out of their dealings with one another, social relations and hybrid phenomena", concluding that:

> "*Of the many reasons for anthropology to engage with what Euro-Americans perceive as science and technology, one is to query the ethnocentric rhetoric that celebrates the joining of life (body) and technology (machine) as though humanity were thereby to be transcended*" (Ibid.: 226).

Although Strathern is partly informed by Melanesian culture, and my research took place in a Western European setting, I take her perspective as my starting point. Researching machines (technology) linked to bodies (people) led me to the specific literature on science and technology, while at the same time, partly thanks to Strathern, I realized that I am not studying a new topic in anthropology: people have always been hybrids, and advanced technology only makes it more visible and explicit.[2] To Latour's "we have never been modern" (Latour 1993), stating that unlike our theories, in our practices we have never been able to divide between the natural and the cultural/ social (however this need not be a bad thing as life is intertwined)[3], I could add, paraphrasing Strathern: "We have always been cyborgs".

Concepts such as 'hybrid' and 'cyborg' point to duality. To celebrate instead the achieved coherence, I aim to avoid two tempting dualisms: the mind-body dualism and the human-machine dualism. I aim to do this by not focusing on the essence of things but rather on the practices they exist in. Instead of taking mind as confronting body and vice versa, instead of binary oppositions between essential entities, a focus on practices shows 'realities' in context, with noise, colour, change of shapes, chaos; and in chaos: coherence (see Mol, below). But here I already draw on other people's ideas, so I turn to the literature.

---

[2] The OED states: " Hybrids: 1601. [- L. *hybrida*, offspring of a tame sow and a wild boar, one born of a Roman father and a foreign mother or of a freeman and a slave.] **A.** *sb.* **1.** The offspring of two animals or plants of different species or varieties; a half-breed, cross-breed. **2.** *Transf.* and *fig.* Anything derived from heterogeneous sources".

[3] See also Mol 2002: 30-33.

When a technological device is continuously worn on the body, the 'mind-body' dualism is closely intertwined with the 'human-machine' dualism. As the attempt to avoid dualisms informed my approach in ethnography —concretely, by studying people's relation with technology from an embodiment perspective— I discuss the literature through this same lens. While for 'mind-body' I mainly focus on literature in the field of anthropology of health and illness (medical anthropology), and for 'human-machine' on anthropological and sociological studies of science and technology, both intersect in anthropological studies on medical technology.

1. Mind-Body Dualism

Perhaps, rather than wanting to 'avoid' the mind-body dualism, I should say that I want to steer clear of taking it as essential or ontological, instead favouring a non-dualist, experiential consciousness of the world.[4] Why?

Initially because, like so many other anthropologists in the medical field, I was inspired to redress the *power balance* caused by the objectification of the body by doctors and biomedicine, by bringing the patient and her narrative into the equation. However, as philosopher Annemarie Mol notes, this holds the risk of confirming the mind/body or culture/nature divide: if it is doctors and physical scientists who talk about the biological body, science, *facts*, then social scientists can only talk about what people think, and say, *interpretations* (see below). Another reason was to bring *experience* to the fore, the patient's individual experience, as the individual lives the illness and is whom we meet. A third reason, closely linked to the previous, was to focus on *practices*, how we engage with the world, in order to counterbalance a privileging of cognitive processes and interpretations. Three reasons that informed my theoretical stance *before* fieldwork.

Over time, as fieldwork progressed, it became apparent that the mind-body dualism as such was not a dominating paradigm to the young people with diabetes.[5] I rephrase, it was not a dominant paradigm in their discourse, what is more, they did not

[4] See Evens' entry "phenomenology" in T. Barfield (ed.) 1997 *The Dictionary of Anthropology*. Oxford: Blackwell Publishers (pp. 353-355).

have a discourse on their illness, they lived it. They lived diabetes, and lived conflict —with diabetes rather than their bodies. The young people did not have a ready narrative on which to embark relating their reflections on the illness, centred on cognitive models, reclaiming their bodies, situating their selves. Thus when I asked them to tell me about living with diabetes, they shrugged and replied there was nothing to say.[6] I relate this absence of a ready discourse mainly to their age. Firstly, they have not been socialized in it. [7] Apart from short occasions in the doctor's consultation, most young people are not invited to talk about their diabetes (at home and with friends), and are not in the habit of doing so.[8] Secondly, in adolescent years it is not 'cool' to talk about something that debilitates you. Diabetes is mostly a sleeping lion, always present, but nothing spectacular to recount.[9] Instead of embarking on a narrative, they told me to ask questions and they would answer (or not) with short sentences, or 'yes' and 'no'.

My theoretical focus on the patients' stories (individual experience and practices) combined with the fieldwork 'reality' of the absence of young people's reflections, and again I stress the continuous cross-fertilization between the two. The more I spoke to the young people, the more I looked for an approach that would fit with their experiences, their life-world. I thus resolved to focus on how they 'did' diabetes in their daily existence.[10]

Hence the concept of 'embodiment': allowing me to foreground the young person (not just the biomedical description of diabetes in the body) with his/her individual experiences and practices involved with diabetes and wearing a pump. Embodiment provided the theoretical way in and the solution to my qualms with the mind-body dualism. I take a broad approach to embodiment: the way we live life

---

[5] This in contrast to how most *adult* patients spoke to me about their diabetes and their experience with the insulin pump.

[6] They had all voluntarily agreed to an hour interview at their home, arranged in advance, and were aware I wanted to talk about their life with diabetes. The question did not come at an awkward moment catching them in the middle of things.

[7] Of course it also depends on their personality, relation to their illness, mood, and feelings.

[8] This is a generalizing sketch of the bulk of the people I spoke to in Millness. The difference with centres in the US, Belgium and Sweden is striking, where many young people *do* discuss diabetes and its management with their parents and doctors, and consequently talk fluently about life with diabetes. They have a narrative. Add to this, as described to me by Scottish people as 'typically Scottish', the fact that young people are shy and not eager to talk to (unfamiliar or authoritative) adults.

[9] In contrast are those heroic tales linked to their diabetes and readily narrated to all, the funny stories, or the dramatic ones that are made entertaining afterwards (usually a theatrical fainting episode, or what they were up to when being extremely high or low in blood sugars).

[10] I have to admit that this information was mainly acquired through interviews, thus by talking (interpreting, making sense of) about practices, instead from observing practices.

'embodied': with and through our bodies. I see it as a road towards reclaiming the body in our lives, to making it present. However, how much and how it is present varies in every individual and at every moment. A constant to-ing and fro-ing. And here I am back at my disclaimer from the start, about not wanting to completely avoid the dualism. I think, in the West, and in this case in Millness, we live with the legacy of Cartesian dualism: the mind-body distinction is 'good to think with' and so we do. Can I say that the mind-body dualism is our Western modality of embodiment?[11]

I start by sketching Merleau-Ponty's concept of the body-subject, as it is the inspiration for the notion of embodiment I (as many phenomenological anthropologists before me) employ. After situating anthropologists' pull to the philosophical tradition of phenomenology, I point out a particular problem with how the embodiment concept is used by some, and I look for another way, more true to the phenomenological spirit. I find this other way concretely in some fascinating ethnographic studies and I conclude with the writings of two philosopher authors, Katherine Young and Drew Leder, who offer a theoretical framework to deal with mind-body dualism in a satisfying way.

1.1 Merleau-Ponty's Body-Subject[12]

Philosopher Merleau-Ponty's seminal work *Phenomenology of Perception* (1945) has become a major inspiration to anthropologists focusing on embodiment and bodily praxis. [13] His ideas on the human body are to be situated in his broader critique of the 'Objective thought' of empiricism and intellectualism —concretely, how they think the

[11] After a long struggle to avoid the dualism, in the end I realized that it would be artificial (when writing about Western culture) to overlook it, as this seesawing between mind (consciousness, self, soul) and body is a constant lived reality. I resolved to start from what matters to the people involved and give place to their activities, practices, and routines together with their fears, doubts and thoughts. Thus, the fact that we 'hang together', as body plus mind, is seen as an achievement. Hanging together takes continuous effort and breaks down in the case of illness, when the body stops functioning in its usual 'tacit' mode anymore, and interferes (see Leder below).

[12] To keep the main text flowing I put any clarifications in the footnote text.

[13] Together with Heidegger and Sartre, Merleau-Ponty was a student of the founding father of phenomenology, Husserl. Husserl posited the 'phenomenological epochè' (bracketing), which means to put aside (philosophical realism's) assumption of a 'real world' that exists separate from what we perceive and think about. My discussion of Merleau-Ponty's phenomenology and his ideas concerning the human body is primarily based on Hammond (1991) *Understanding Phenomenology* and on Dermot Moran's (2000) *Introduction to Phenomenology* (Chapter 12: Merleau-Ponty). Since I quote from the English translation of *Phenomenology of Perception*, page numbers refer to the 1962 English edition.

world is *like*[14] 'the Universe'— against which he posits the 'lived-through-world' which is encountered in the phenomenological approach. [15] People are at home in the 'lived-through-world'. The body —Merleau-Ponty uses the term "le corps-propre" (one's own body)— cannot be studied by 'Objective thought' because this way of analysing the world does not recognize the *active and purposive* nature of the body, its practical orientation towards the world (Hammond: 165). Merleau-Ponty argues that the human body is not an object; unlike other objects the body changes (has indeterminate properties), defies causal explanations and most importantly "its spatiality is that of situation rather than location" (Hammond: 162). Instead the body is the *subject* of action, through its preconscious and practical knowledge and intentionality. [16] The body possesses practical knowledge 'praktognosia': "My body (...) understands its world without having to make use of my 'symbolic' or 'objectifying function'" (M-P 1962: 138). The body also possesses *intentionality*, it thus defies scientific explanation as it is not merely a mechanical organism.[17]

Through the body-subject and the primacy of practice, Merleau-Ponty rejects the intellectualists' conception of the subject as a disembodied consciousness: "Consciousness is in the first place not a matter of 'I think that' but of 'I can'" (M-P 1962: 137). (I take Merleau-Ponty's concept of intentionality (the body-subject holding sway in the world, being geared towards the world) as a key-concept and as what some social scientists inspired by phenomenology do not account for in their analytical use of 'embodiment'(see below). Consequently, in my approach to the young people and pumps, I take consciousness as in the first place not a matter of 'I think that' but of 'I can'.) This has brought me to the *mind-body dualism*, a concept to which the name of Descartes is indissolubly linked.[18] Descartes conceives of the human body as the

---

[14] Note: the 'like' is crucial. Empiricists and rationalists do not agree on the ontology of the world, but they both see the world (nature) as separate from our perception of it.

[15] Part One of *Phenomenology of Perception*. I base this discussion on Hammond: pp162-177 'The Peculiarities of one's own body'.

[16] Thus Merleau-Ponty undermines the idealists' conception of the subject: the thinking ego, the ethereal mind.

[17] So it cannot be understood (as Objective thought does) scientifically by looking at causality (an external relation), since intentionality is an internal relation (which can only be explained by reference to each other). The basic intentionality of the body is motility "that which is involved in one's ability to act on the world. In such action it is one's body which is 'directed towards' that world" (Hammond: 180).

[18] Descartes (1596-1650) philosopher and mathematician, 'Cogito ergo sum' 'I think therefore I am'. He doubted all the senses; thinking was the only criterion for truth. —As philosopher Katherine Young phrases it, he saw self-reflection as "the constitutive experience of personhood" (Young 1997: 130). However, Young reminds us that Descartes would disagree with how we interpret him (i.e. the notion that the body is an object). We only took from him the opposition between mind and body (two substances different in kind), we left out his struggle for a way to link them. (It was only after wrestling with the

physical body from Galilean science (Hammond: 158), to which an ethereal mind is added.[19] Doubting all sensory data, Descartes concludes he can only be sure of the fact that he thinks and thus exists. In place of this thinking ego as the 'true subject', Merleau-Ponty puts the body-subject that is always already-in-the-world (Hammond: 162).[20] Since 'Objective thought' does not account for the specificity of the human body, Merleau-Ponty proposes a different approach:

> "Another kind of thought, that which grasps its object as it comes into being and as it appears to the person experiencing it with the atmosphere of meaning thus surrounding it" (M-P 1962: 120).

1.2 Anthropologists and Phenomenology

How come anthropologists are drawn to the philosophical movement of phenomenology? I consult the writings of two protagonists of 'phenomenological' anthropology: Michael Jackson and Thomas Csordas.[21] Both Csordas (1994, 2000) and Jackson (1989) react against the language of representation of which they see Geertz with his 'interpretive anthropology' as one of the major players in the 1970's. Geertz (1973 *The Interpretation of Cultures*) defined culture as a 'system of symbols' that could be read as a text. Representation comes to constitute experience, and the notion of experience, once reduced to language and text, is lost. In the 1980's a critical wave rose against this dominating language of 'representation', both in feminist and philosophical

---

incommensurability of a purely material body and a purely insubstantial mind that Descartes concluded that the body is, in its primary presentation, an idea in the mind)(Young: 134). Young explains that the difficulty for Descartes was: starting from either the mind or the body, how can we arrive at the other? She quotes Descartes: "Nature teaches me by these sensations of pain, hunger, that I am not only lodged in my body as a pilot in a vessel, but that I am besides so intimately conjoined, and as it were intermixed with it, that my mind and body compose a certain unity" (Descartes [1641] in Young: 135).

[19] This relates to the mind-body problem as investigated in the 'Philosophy of Mind': 'can intentional states be explained in terms of non-intentional ones?', though as Hammond states, for Merleau-Ponty this was a body-body problem. In *Phenomenology of Perception* he investigates the curious connection between the intentional states of the body and their supposed neurophysiological basis (Hammond: 278).

[20] In other words, where scientific realism says that a subject-independent world does exist, (and the empirical sciences have a privileged status in explaining what happens in it), phenomenology says that there is *no* subject-independent world. (While Husserl states that the only real world, which has ontological priority over the scientific world, is that which is pre-scientifically experienced —he calls this the 'lived world' of which sciences make an abstraction— so there is always a subject already *in* it, otherwise there would be no world (see Hammond: 271-279).

[21] I base this account on Jackson (1989) *Knowledge of the Body* and Csordas (1994) Introduction to *Embodiment and Experience* and (2000) 'The body's career in anthropology'.

writings.[22] In anthropology the critical movement can be bundled under the name 'reflexive' anthropology. As Csordas (1994) notes, this category houses the Writing Culture debate (Clifford, Marcus, Fischer) (which propagated alternative forms of representation), the postmodern movement (which aimed to 'evoke' instead of 'represent'), and phenomenological anthropology. These latter anthropologists found an alternative to representation in the philosophical movement of phenomenology, more precisely its concept of 'being-in-the-world'. They reclaimed the notion of experience by a new methodology that aimed to understand culture in terms of 'existential immediacy', instead of in terms of objectified abstraction. In other words, culture *also* resides in bodily processes of perception, not only in objects and representations (Csordas on Merleau-Ponty 2000: 183). Thus through phenomenology, anthropologists put experience and more specifically bodily experience at the centre of ethnography.

Csordas and Jackson, the main inspirators, hold similar positions, although with specific emphases. Csordas defines embodiment as "an existential condition in which the body is the subjective source or intersubjective ground of experience" (Csordas 2000:181). [23] He (1994: 12) stresses the importance of distinguishing between the body: a biological, material entity —with a culture and a history which makes it a problematic notion: object *and* agent— and embodiment: an indeterminate methodological field, defined by perceptual experience and by mode of presence and engagement in the world (1994: 12) "a methodological attitude that demands attention to bodiliness" (2000: 184). He critiques that much of anthropology has been grounded in the Cartesian legacy, privileging the mind/subject/culture set in analysing culture while it is the body that should be understood as "a seat of subjectivity" (1994: 9). For Csordas the issue is "*the manner in which* the body is an existential condition of life" (2000: 181) (my emphasis). It does not suffice to acknowledge that we have bodies, there are multiple modes of embodiment and it is these modulations of embodiment that are critical for the understanding of culture. Thus by investigating embodiment we can approach culture and self.

[22] For example the Philosophy of Agency, the Philosophy of Community (cf. Charles Taylor 1985).
[23] Note also the title of his book: Csordas (1994) *Embodiment and Experience. The existential ground for culture and self.*

While Csordas promotes embodiment as a methodology, existential anthropologist Jackson sees embodiment (and the body) as a topic in its own right.[24] In response to the semantic model that has dominated anthropological studies of the body, Jackson outlines a phenomenological approach to body *praxis*: "human experience is grounded in bodily movement within a social and material environment" (Jackson 1989: 124). He blames the language of representation for its tendency to interpret embodied experience in terms of cognitive and linguistic models of meaning. Instead of seeing the body as a "thing onto which social patterns are projected" (Ibid.: 123)[25], he puts forward Merleau-Ponty's notion of intentionality. "Consciousness is a being-towards-the-thing through the intermediacy of the body" (M-P 1962: 136). Like Csordas, he critiques the Cartesian divide between subject and object that implies that the human mind is the sole locus of subjectivity. Instead, Jackson proposes 'bodily subjectivity': "the meaning of a bodily action is not *given to* the action by some external agent but is *in* the action itself" (1996: 32) (my emphasis). In phenomenology Jackson finds that "knowledge of the mind is neither ontologically prior nor superior to knowledge of the body. (...) Our gestures and actions do not invariably depend on a priori cognitive understanding (on the contrary) in most human societies knowledge is a matter of practical competence" (1996: 34).[26]

Though the present ethnography is on a Western society that favours theoretical knowledge and cognitive processes, as it discusses young people and close-to-the-body technology, a focus on practical competence proved both appropriate and enlightening.

Here I like to mention a problematic point —as clearly spelled out by Hammond (1991: 275) — in some social scientists' adoption of phenomenology. Husserl and Merleau-Ponty critique scientific realism because it *separates humans from nature* and so removes from the world all those characteristics that make the world meaningful to

[24] He states how embodiment is as much "a primordial aspect of human subjectivity as it is of sociality"(1996: 32), this fits in his existential anthropology and emphasis on intersubjectivity.
[25] This is still the case, even in writings of anthropologists waving the 'embodiment' flag. For example in *Death Without Weeping,* Nancy Scheper-Hughes (1992) takes the body mainly as a creature of representation: as having a communicative function. While communicative means disadvantaging the more existential and direct functions of the body, it also de-individualizes it, as the communicative function is usually seen in the context of social abuses (or for example to protest against medicalization). Not giving meaning and primacy to one individual body but seeing it (and its power and significance) as one of many (see below).
[26] Jackson is thus very critical of anthropologists who prioritise theoretical knowledge, for they reduce a complex activity to the mechanism which lies underneath and which is unknown to the participants.

our pre-scientific everyday life experiences, locating them instead in people's minds. However, social scientists who critique scientific realism because it uses scientific methods to study the human world and instead emphasize the need for a non-scientific description of the human ego and meaning, because of the 'subjective' character of human existence, do exactly the same: they separate humans from nature. When they then employ phenomenological concepts as a base for their social science it is rather problematic, as they accept precisely what phenomenologists are concerned to reject: the distinction between subject (subjective human experience) and object (objective nature). —This is a tricky point to make, because I don't think I come away unscathed.[27] However, this issue helps me to understand my unease with some anthropological studies of health and illness taking inspiration from phenomenology that celebrate the 'experiencing body' while prioritising cognitive processes and social and cultural forces. —Are these social scientists Latour's 'modern' scientists, who distinguish between a subject that actively knows (the social) and the object that is known (the natural)? Latour (1993) says we have never been modern, nor should we aim to be, and we can escape out of this nature/culture divide by realizing that the world we live in is a mixture (Latour in Mol 2002: 31). [28]

Is a similar point, as Hammond's, made by philosopher Annemarie Mol when she critiques the urge of social scientists, in the 1950's (after the eugenics disaster of the second world war), to create alongside the biological domain, studied by physical scientists, a separate social domain to be studied by social scientists —with the underlying assumption that while biology is the same, the differences we perceive are cultural and social (Mol 2002: 16)? Mol explains how this led to anomalies in studies of race, kinship and sex. For example, if social scientists can only talk about (differences

---

[27] I try to downplay this separation human/nature by employing a bottom-up approach, starting from the individuals engaged in/with their worlds.

[28] This coincides with anthropologist-psychologist Benny Shannon's (1993: 94-107) critique of (what he calls) 'representationalists' who ignore the body and the world, by seeing them as external to cognition since all cognition happens in the head. This creates an 'unbridgeable gap' in representational models, between two levels of reality (mind/cognition/cognitive agent versus world) while in the phenomenological reality there is no gap: people interact with the world. Thus representational models miss out on capturing the essence of cognition i.e. understanding. By defining understanding as "to manipulate symbols" they miss out on what is saliently human (consciousness and experience). Representational models are suited to talk about computers, not people, as they disregard the phenomenological body (for example arms, hands) which plays a crucial role in cognitive activity (motor-activity, memory, senses), knowing how to do something by acting it out (but not able to say the rules): body = the union of the subject and the world.). Shanon refers to ecological psychologist J. Gibson (1979) "[t]he world that is perceived cannot be defined independently of the agent that perceives it and the world is structured by the activities of the perceiving agent" (Shanon 1993: 122). As Drew Leder (1990: 34) states: we learn to swim because the lake invited us to do so.

in) gender, then sex is taken as carved in stone. Mol concludes that unless social scientists are happy with only providing weak interpretations about biological 'facts', they need to also talk about biology. She gives the example of the medical world: "[a]s long as disease is accepted as a natural category, and left unanalysed, those who talk in its name will always have the last word" (Ibid.: 16). Running ahead, Mol propagates an ethnography of practices, to escape this dialectic stalemate (see below). This is not merely a theoretical trick, it is instead dealing properly with life as it is: "in our daily lives we are engaged in practices that are thick, fleshy and warm, as well as made out of metal, glass and numbers" (Ibid.: 31).

To sum up.
Merleau-Ponty situates knowledge and intentionality in the body, concretely with the concept of praktognosia and the stress on bodily praxis. Two things. First: in ethnographies by some anthropologists claiming the legacy of Merleau-Ponty's phenomenology and embodiment, instead of in the body, knowledge and intentionality seem to be solely located in the mind. Second: how can I myself try to avoid this? Why do I want to? This is not a matter of being a 'phenomenological' purist, but rather seeing Merleau-Ponty's stress on practices and the body's pre-conscious knowledge of the world as useful and appropriate, both for my view of the world and for the people in this ethnography. So what I take from phenomenology and in particular Merleau-Ponty, is a need for, and a way to, *redress the balance*. The balance that in the Western world has keeled over to the mind. A focus on bodily experiences, practices and feelings can rebalance the scales, and means that I have to refrain from presupposing two distinct entities, mind and body, though they will often appear, as dualism is our dominant modality of embodiment. At the same time another balance is redressed: the individual (through their body, feelings, consciousness of things) is made explicit and central in the wider communal context of social and cultural forces.

1.3 Phenomenological Ethnographies of Health and Illness

I now turn to some ethnographies by anthropologists writing on health and illness, who state their indebtedness to phenomenology. After illustrating my issue with a concrete example, I turn to other studies that use embodiment in an inspiring way.

I mentioned the problematic use of phenomenology by some social scientists. In stressing the non-scientific description of the subject and of meaning, they (mistakenly) accept the separation subject-object. Initially I thought that this was what perturbed me in the accounts of some anthropologists. Though now, having written about Jackson, I think my issue is better described in Jackson's terms, as their "tendency to interpret embodied experience in terms of cognitive (and linguistic) models of meaning" (Jackson 1989: 122). Is this related to the separation of the subject and object? I presume it is. If subject and object are separated, the body (its experience and our experience of it) is merely a special object of which the subject makes sense in mental processes.[29] Thus bodily knowledge and praxis are not given full weight. As said before, I am fearful of the scales being tilted in favour of the mind.

A concrete example is Nancy Scheper-Hughes' (1992) approach to the diseased body in her book *Death without Weeping*. She describes how sugar cane workers in a Brazilian shantytown do not refer to their extreme deprivation with the term 'hunger', but with the idiom 'nerves' (nervos). People are unable to work, and faint not of hunger but of nervos and they treat themselves by 'eating' medicines instead of food (which they cannot afford). They came "to see themselves primarily as nervous (and only secondarily as hungry)" (1992: 177). Scheper-Hughes explains this shift in popular discourse on hunger to one on illness by the process of medicalization: when illnesses mainly caused by social relations are defined in neutral biomedical causes. By medicalizing an illness, all power of criticism and rebellion is taken out of a social situation. The 'nervos' discourse provided a safe way for the shantytown people to express their anger, as political protest was dangerous. Scheper-Hughes' ethnography is to be located in her plea for a critical applied medical anthropology.[30] One of its main tasks is to act against medicalization —which medicalizes and privatises social relations contributing to illnesses— by politicising and collectivising these social relations. The (my) problem is that a 'politicise and collectivise' agenda does not leave much space for the individual body, let alone the body as experiencing agent, which is another

[29] I only touch tangentially on the concept of the body in anthropology (as only seen through the lens of embodiment and dualism). For a comprehensive overview of the 'body in anthropology' see the articles by Csordas (2000) *The body's career in anthropology* and Lock (1993) *Cultivating the body: anthropology and epistemologies of bodily practice and knowledge.*

[30] See Scheper-Hughes 1990 and Lock & Scheper-Hughes 1996.

campaign point that Scheper-Hughes holds dear. I do not see how the two can be combined successfully, while doing justice to the body. Instead the body is seen as a means to an end, the body is a starting point, but not a subject in its own right. In the shantytown, Scheper-Hughes sees the bodies of the workers as communicative: they give a message that can be used. Are we not back at the language of representation, the body seen as a thing onto which social patterns are projected? Even if the movement travels in the other direction (body to society) we are in the same theoretical scheme. The practice of the body is not central and a thing on its own. While Scheper-Hughes pleads against anthropologists considering the body "as a passive participant, attached to a lively mind, the true agent of culture" (1996: 42), it seems she does exactly that. We see this in her definition of medical anthropology as "the way in which all knowledge related to the body (and health and illness) is culturally constructed" (1996: 43) and in considering 'bodily praxis' as of "someone living out and reacting to her place assigned to her in the social order" (1996: 65). Does this not make the body passive vis-à-vis culture?[31] While Scheper-Hughes talks highly about "the sentient body" and "the body as primary action zone", the concept of the body she uses in ethnography is very *mind*ful. Not wishing overly to criticize Scheper-Hughes' fascinating work, I merely take this respected medical anthropologist as an example, to show how confusing and difficult it is to honour this 'bodily praxis' without lapsing into privileging the mind acting upon and making sense of it.[32]

Collectivising and politicising does not leave space for *individual experience.* Other anthropologists consciously choose to do so.[33] A medical anthropologist who criticises politicising is Arthur Kleinman (1995, 1996). He judges the interpretive turn in anthropology (as criticised by Csordas and Jackson), which treats illness as a socially constructed reality, to be (guilty) of professional transformation of illness. It "delegitimizes the patient's suffering" (1996: 169). Instead Kleinman proposes a contextual focus on experience, which looks at *what is at stake* for the person studied (Ibid.: 172). Concretely Kleinman does this in the case of Huang, a young worker in rural China who suffers from depression. Instead of interpreting Huang's depression as

[31] Nigel Rapport, personal communication.
[32] As Jackson's quote above: the tendency to interpret embodied experience in terms of cognitive models of meaning.
[33] For example in *Tuhami* (1980) Vincent Crapanzano tells us the gripping life story of a mentally (and physically) suffering Moroccan tilemaker.

a "somato-psychic idiom of distress that expresses the psychological effects of political problems in a politically acceptable and culturally sanctioned collective rhetoric of complaint" (178), which would turn Huang into a passive object, Kleinman focuses on what was at stake for Huang: this was the shame, the injustice, Huang's frustration of being unable to right a wrong. (At the age of 12, Huang had been wrongly accused of writing an anti-Mao pamphlet that had him sent to a farm for a year to be re-educated by harsh labour. Huang was not guilty but unable to tell anyone, even his mother.) Kleinman concludes that looking at what was at stake here "tells us something more valid about Huang's actual experience of suffering than separate cultural, political or psycho-dynamic interpretations" (Ibid.: 179).

Other medical anthropologists choose to focus on the *physical body* as a site of *experience*, —rather than, as Scheper-Hughes, on its communicative function— and thus write on the many aspects of the changing relationship between body and self in times of illness. I discuss three poignant studies by anthropologists Sharon Kaufman, Donald Moss and Jean Jackson.

In her study of Mr. Brown recovering from a stroke, Sharon Kaufman (1988) states that illness should be understood as "an experiential event, grounded in subjectivity" (1988: 340), as well as in biological and social events. She draws on philosopher Sally Gadow's (1982) work on the changing relationship between the body and self during illness. When a body is seriously ill, this relation could be called one of "disrupted immediacy", which is characterized by incapacity, the self being limited by the body's restrictions. This is the condition in which Kaufman first meets Mr. Brown, a few weeks after his stroke. Kaufman focuses on the significance for Mr. Brown to be able to walk again. In the first weeks, he urgently needs to learn how to walk so he can climb the stairs to his office "I am the boss, I have always been the boss, I get things done". Five months later, when his employees bring his office work to his bedside, walking takes on a new significance "If only I could walk, so I could get to the bathroom, so my wife wouldn't have to bring me the urinal, and so I could go into the kitchen and make myself a cup of coffee" (Ibid. 344). Kaufman calls this an 'existential transformation', walking had become the symbol of personal autonomy. Mr. Brown emphasized that "his interpersonal relationships had become the source of his feeling crippled" and saw his dependency upon others as a threat to his identity. Kaufman

concludes that perspectives of therapy and need change when "new body images take hold through which people re-evaluate loss and progress" (Ibid. 345).

This troubled relation between body and self also features in Donald Moss' study on obese women's 'dealings with their bodies' (1992). Concretely these 'dealings' come down to the women encountering their body as an object —in medicine (pathology), in society (stigma) and by the patient (body out of control)— and struggling towards transcendence "a yearning of people to be valued as more than devalued bodies" (Moss: 191). Moss states that this struggle for transcendence is basic to human existence.

A similar process can be found in Jean Jackson's (1994) study on patients trying to cope with chronic pain. Jackson states that chronic pain challenges the notion of body as object and self as subject. The 'lived pain-full body' confounds people. The patients try to restore the dualism by 'cognitive restructuring': the cognitive psychological patterns through which to control the pain, either by objectifying it (pain as object, pain with agency, a monster) or by subjectifying it (the pain is only in my head). Jackson introduces a continuum: on one end we find the self apart from pain (pain is an alien, an invader), on the other end we find the identification of the self with the pain (pain experienced as coterminous with the body).

Even when focusing on the individual body, we are unable to avoid the mind-body dualism. Because this is how Western subjects live and deal with illness: by making sense of it. Dualism seems a powerful tool to 'get to grips' with what threatens our identity, it is a strategic practice: "Cartesian dualism is real inasmuch as people act as if it were".[34] Thus I have to accept mind-body dualism as epistemology, as medical anthropologist. As phenomenological anthropologist, I deal with it as part of that life-world which is bracketed off from whatever may or may not be ultimately true.

---

[34] Nigel Rapport, personal communication. I thank Nigel for pointing this out to me so succinctly and making 'dealing with dualism' easier. See also Michael Jackson (at the end of this chapter) on dualisms. "Although we may ontologise, essentialise, reify or actively deny the symbolic contrast between culture and nature, or self and other, it is important to see these contrasts as part of the rhetorical strategies we deploy in struggling to strike a balance between our familiar, local worlds, in which we feel we have the right to command our own destinies, and a world of otherness, governed variously by global forces, by

Philosopher-cum-medical anthropologist Katherine Young states: "our epistemology of the body is Cartesian. We tend to think of the body as a sort of solid object and of the self, and in particular the mind, as a sort of ethereal subject mysteriously infused into the object" (Young 1997: 130). Young, together with medical doctor-cum-philosopher Drew Leder, offers me the most inspiring approach to this dual epistemology. In *Presence in the Flesh* (1997) Katherine Young describes patients' experiences of embodiment in patient-health carer interaction in several medical practices: consultations, gynaecology, surgery and pathology. She explains the dualism experienced by the patients as follows. She states that in our experience of embodiment the body is never reduced to a physical object (realism), nor etherealised into an idea (idealism). Young quotes Leder to explain how "[t]imes in which the body is most tacit and self-transcending are collected under the rubric of rational 'mind'. Other experiences where corporeality comes into strong thematic presence, are collected under the rubric of 'body'" (Leder in Young: 131). Young claims that the mind-body distinction is not the proper contrast; instead she introduces the 'experience of self' into the equation and suggests the contrast between body-as-self and body-as-object. If we visualize a spectrum of possibilities of embodiment, in the centre we have the embodied self (= the body as self); if this is out of balance, we experience the body as object, this experience can go to the two opposite ends of the spectrum: one is etherealisation (the self is lifted out of the body), the other is materialisation (the body is dispossessed of the mind).[35]

embodied self=

body as self

e.g. harmonious social self

etherealisation=	materialisation=
body as object	**body as object**
(disembodied mind)	(mindless body)
e.g. cognitive restructuring of body	e.g. pain obliterating mind

The 'body as object' is not the natural order of the body, but a "specialised inflection" given to the body by several discourses, one of which is medicine (Ibid.: 136).

---

the gods, by contingency or elemental powers, in which we feel far less in command, and of which we have far less understanding" (Jackson 2002b: 343-344).

[35] My representation, based on Young's text.

Thus for Young the distinction between 'body as subject' and 'body as object' is incorrect. We cannot conceive of the 'body as subject': "[A]s soon as we turn our attention to it, we become aware of the body as an object.(...) We cannot turn our attention to the body as subject, as subject, the body is what we turn our attention *from*" (Ibid.: 135). Likewise, it is not our 'body as object' we are aware of when we are confronted with our own materiality (as in medicine), rather, we are aware of "the corporeality of the self". "I am not enveloped in materiality, but materialized corporeally" (Ibid.: 135). And thus we are "precipitated into our own skins, neatly embodied, acutely present in our own flesh". Young's approach enthuses me as it addresses several issues I have with the dualism. By putting the 'self' centre stage (individual) with his/her experiences and the making sense of things (salient human properties), she manages to combine body and mind "the body is not divorced from thought but continuous with it, sometimes obtrusive and sometimes recessive in our experience of thinking" (Ibid.:134).

Another inspiring approach to the concept of embodiment I encounter in the writings of Drew Leder, already cited above by Young. In *The Absent Body* (1990), Leder makes it his mission to challenge the 'onto-valuational' Cartesian dualism, both because it is wrong and because by privileging mind over body it leads, he claims, to negative social consequences, such as oppression of women and 'primitives'. To summarize the book in one sentence, he explains that Cartesian dualism is so successful because of our experiences of bodily absence that he sees as the essential structures of embodiment.[36] His argument is that human experience *is* incarnated, but often paradoxically, as our own body is seldom the object of experience, and instead we experience 'corporeal absence'. Leder (Ibid.: 1-8) critiques most phenomenological studies of embodiment for focusing on perception and motility: modalities through which we directly experience and act upon the world. However, these modalities "arise in impersonal horizons" such as the "autonomous rhythm of breathing and circulation" (Ibid.: 2). Leder makes a strong case for including these experiences of bodily absence,

[36] The whole argument is that the tendency in Western intellectual history towards disembodiment (from Plato, through Descartes) has been supported strongly by our experiences of bodily absence. In *The absent body* Leder gives a phenomenological account to show why Cartesian dualism is so persuasive. He describes our three different experiences of bodily absence: on the surface of the body: sensorimotor powers open up the world (e.g. eyes), in the depths of the body: visceral organs (e.g. I do not recognize my heart), and mixed presence and absence: the body appears at dysfunctional times (illness, pain), while

and suggests a concept of embodiment that avoids dualistic presumptions[37]. This is his notion of 'the lived body'. In addition to the 'standard' phenomenological concept of embodiment, 'the lived body' includes the body as an *object* (available to external gaze), the *physical* body (the perspective of empirical science) and the body as a seat of *intellectual thought*. Thus 'the lived body' sees the embodied person from both the 1st *and* 3rd person perspective, as 'articulated' by both science *and* the life-world gaze, and combines intellectual activity with visceral and sensorimotor capacities (Ibid.: 6-7).[38]

Before embarking on the second dualism, let me sum up how I dealt with the mind-body issue. Though I said I wanted to avoid mind-body dualism, I cannot, as the above discussion has made clear, both because it is not feasible or desirable. The discussion has also shown why my ethnography should focus on the young people's stories, stressing their individual experiences and intentionality, how they are in the world through their bodies, and looking at what is at stake for them.

Phenomenology helps me to step away from the thinking framework of on one side the world (with our body) as physically out there and, on the other, people interpreting it. In this framework the main relation is dual (harmony or conflict between two), as at the base of it all there is an essential difference. Seeing the human body in its intentional state 'geared towards the world' in the 'lived-through-world', provides a wider scene from the start, in which there is movement and pulling and pushing. In this frame I introduce the human-machine relation: instead of separate entities, I take technologies (concretely the insulin pump technology) as embedded and working in and through relations between people (pump wearers, their family, friends, health carers), practices (eating, sleeping late, sports, clinic consultations) and objects (pump, needles, blood test print outs, insulin, food, clothes).

---

it tends to disappear when it is functioning well. I will take up the idea of the absent body further in Chapter 8.

[37] Since there are the constant dangers of new dualisms which can again partialize the notion of the lived body, as has happened in many 'phenomenological' studies.

[38] Leder developed this notion of 'the lived body' in his campaign for a 'medicine of the intertwining' (Leder 1992 *A tale of two bodies: the Cartesian corpse and the lived body*), which looks at existential levels of biological outcomes and vice versa, to show that disease has an existential dimension. While I may have given the wrong impression that he arrived at the 'lived body' by adding aspects to the phenomenological concept of embodiment, he actually came to it from the other end: by adding the existential and intentional aspect to the Cartesian 'machine-like' body. "To attend to the lived body is not to forsake the tools and learning that Cartesian medicine has provided. It is merely to refuse to grant this mechanical wisdom the status of ruling paradigm" (1992: 31).

How does this relate to the literature on people and technology?

2. Human – Machine Dualism[39]

Man-the-machine

"The great book of Man-the-Machine was written simultaneously on two registers: the anatomico-metaphysical register, of which Descartes wrote the first pages and which the physicians and philosophers continued, and the technico-political register, which was constituted by a whole set of regulations and by empirical and calculated methods relating to the army, the school and the hospital, for controlling or correcting the operations of the body. These two registers are quite distinct, since it was a question, on the one hand, of submission and use and, on the other, of functioning and explanation: there was a useful body and an intelligible body."

M. Foucault (1979) *Discipline and Punish*: 136

This quote from Foucault puts the topic of bodies and machines in a timeframe. The concept of Man-the-machine originated in the 17th Century and led to projects of docility, Foucault's so-called 'disciplines' "the body is docile that may be subjected, used, transformed, improved" (Foucault 1979: 136). These gave rise to an 'art of the human body', dedicated to making the mechanism more obedient and more useful and to a 'political anatomy' "it defined how one may have a hold over other's bodies, not only so that they may do as one wishes, but so that they may *operate* as one wishes, with the techniques, the speed and efficiency that one determines" (Ibid.: 138). Is then the need for Strathern to point out that there is nothing post-human about a hybrid

[39] I do not venture into specific anthropological writings of technology as this would lead me into a vast domain of issues that are not really at stake here. Instead I looked for inspiration to make sense of the close relationship between people and electronic technology and thus here I mention the authors who have inspired me: they are found in the disciplines of cyborg studies, and more widely science and technology studies.
For an overview of anthropology of technology see the comprehensive article by Pfaffenberger (1992) in which he discusses the relatively recent concept of the 'sociotechnical system' in the anthropology of technology. It critiques the 'Standard View of Technology' (dating back to modern anthropology) that operated along the lines of 'necessity is the mother of invention' and which sees the history of technology as a unilinear progression from tools to machines. Instead, the 'sociotechnical system' is "a universal conception of human technological activity, in which complex social structures, non-verbal activity systems, advanced linguistic communication, the ritual coordination of labour, advanced artefact manufacture, the linkage of diverse social and non-social actors and the social use of diverse artefacts are all recognized as parts of a single complex that is simultaneously adaptive and expressive"

combination between body and machine to be located in the apprehension, still alive after 50 short years of contestation, of the 300-year-old monster of Man-the-machine?[40]

If I were to follow Foucault's distinction between registers, here I am mainly concerned with the 'intelligible body' (the anatomico-metaphysical register) and that is where my approach through embodiment and phenomenology fits in. However, most authors writing on humans and machines could be located in the technico-political register, contesting the 'useful body'.[41]

Man-with-machine = Machine? The Cyborg

"The cyborg is the figure born of the interface of automaton and autonomy"

Haraway (in Gray 1995: 1)

"*Cyborg imagery can suggest a way out of the maze of dualisms in which we have explained our bodies and our tools to ourselves. This is a dream not of a common language, but of a powerful infidel heteroglossia*"

Haraway 'A Manifesto for Cyborgs' (1985: 101).

Feminist techno-science writer Haraway could easily be located in the technico-political register, refuting the domination of the body (and the world) by the 'White Capitalist Patriarchy' (Haraway 1991: 197), but she also successfully refutes the 'intelligible body'.[42] However I am guilty of an anachronism here for, though her stance is against one-sided control and power, Haraway does not so much react against Man-the-machine but rather against man (in this case mainly woman, the world) as an object of

---

(Pfaffenberger: 1992: 513). See also Pfaffenberger's more recent "Anthropology of Technology" entry (Pfaffenberger 2001).

[40] Understandably, as in our computerized society images of people as machines are rife in the media. For example the Haynes (publisher of car maintenance manuals) MAN manual (November 6, 2002) entirely devoted to men's health, the full title is *Man: 120.000BC to Present day: All Models, Shapes, Sizes and Colours* and the cover shows an adjusted image of Da Vinci's homo universalis. Chapter headings include Roadside Repairs (first aid), Cooling Systems (circulation), Engine Management (the brain), Suspension and Steering (joints) and Chassis and Bodywork (bones and skin).

[41] See also Leder (1992: 5). This is why cyborgs are a frequent topic of many 'feminist' authors, reacting against the tendency in Western 'patriarchal' philosophy to identify the self with disembodied reason (see Leder's critique against the onto-valuational Cartesian dualism, favouring culture over nature) while ignoring the inferior body.

knowledge and thus subjected to the power of 'the knower'. "[T]he analytical tradition (...) turns everything into a resource for appropriation" (Ibid.: 197). Haraway successfully disputes this "appropriationist logic of domination" (Ibid.: 198) built into all known dualisms (including mind-body, human-machine) by the image of the *cyborg*: a technological hybrid that challenges all dualisms.

> "It is not clear who makes and who is made in the relation between human and machine. it is not clear what is mind and what body in machines that resolve into coding practices (...) There is no fundamental, ontological separation in our formal knowledge of machine and organism, of technical and organic (...) These machine/ organism relationships are obsolete, unnecessary. For us, in imagination and in other practice, machines can be prosthetic devices, intimate components, friendly selves" (1985: 97).

Haraway concludes her 'Manifesto for Cyborgs' by saying that taking responsibility for the social relations of science and technology means refusing an anti-science stance, a demonizing of technology (she is referring to activists proposing a return to the holistic organic body) but instead "embracing the skilful task of reconstructing the boundaries of daily life, in partial connection with others, in communication with all of our parts" (1985: 100). Haraway's *A Manifesto for Cyborgs* published in 1985 launched the academic discipline of cyborg studies (also called 'cyborgology') that reflect the "postmodern skepticism about the coherence of systems and the centred, rational and *disembodied* picture of human subjectivity" (Law & Moser: 2001: 3203).[43]

In describing the ideas that helped me to approach the cyborg-like young person with pump, I draw on authors in cyborg anthropology (Downey, Gray, Haraway), 'feminist' techno science studies (Franklin, Rapp, Haraway, Strathern) and studies of science and technology (Mol, Law, Suchman), as they all study critically the relation between organisms and technology.

---

[42] Though Haraway's cyborg, the ironic figure that challenges both the establishment and individualism is mainly a political critical image, here I 'borrow' her ideas for my own project on a more 'person oriented' scale, the hybrid that challenges dualisms and makes partial connectedness explicit.

[43] See for example articles by Escobar (1994), Law & Moser (2001) and the book *Cyborg Anthropology* by Gray (ed.) (1995) for comprehensive overviews of the discipline.

2.1 Cyborg Studies

"*It's not just Robocop, it is our grandmother with a pacemaker*"

Gray 1995: 2

Though I do not fully agree with the above statement, mainly because I doubt that granny would define herself as a cyborg (likewise the young people on pumps would object to being called that), it does draw our attention to the widespread nature of combinations between humans and technology. Gray points out that there is not just one kind of cyborg, the science-fiction cyborgs, such as Terminator or the Six-Million dollar man, but he mentions 'real' cyborgs: "anyone with an artificial organ, limb or supplement, and anyone reprogrammed to resist disease (immunized) or drugged to think, behave or feel better (by psycho-pharmacology) is technically a cyborg" (Gray 1995: 1). Following that lead, 'technically' people wearing insulin pumps can be called cyborgs. Interestingly, the first ever being to be called a 'cyborg' was a white laboratory rat with a tiny osmotic pump implanted under its skin injecting a continuous flow of chemicals (Haraway 1995: X). This is exactly the mechanism of an insulin pump, with the difference that —for now, though prototypes of a 'closed loop' system pump exist and are being tested— some attention from the organism is required in addition to the continuous injection by the pump.

What are cyborgs?

The term is a contraction of 'cybernetic' and 'organism'. Cybernetics, most famous in Norbert Wiener's elaboration of it, can be defined as "a technoscience that explained both organic and machinic processes as part of informational systems" (Gray 1995:4).[44] The word 'cyborg' was coined in 1960 by Clynes and Kline, a chief scientist and a clinical psychiatrist, to refer to "self-regulating man-machine systems" and more concretely "the enhanced man who could survive in extra-terrestrial environments" (Haraway 1995: XV). In the age of space flights, the challenge was to design an organism that could survive away from earth. Instead of having to carry an earthlike

[44] The discipline of 'cybernetics' was developed in the US during the Cold war, with the aim to develop a theory of communication and control applicable to humans, animals and machines. The key idea was to treat organisms and computers as "self-controlled and self-regulating information-processing systems" (Law and Moser 2001: 3202).

environment with him (like oxygen) why not change the physiology of man?[45] From this military and space technology context, in time the cyborg image developed mainly as an analytic concept, as illustrated in Haraway's writings. While the political critical cyborg image does not concern me here, the challenging of boundaries (man-technology) and the ensuing approaches cyborg studies take to 'agency' and 'knowledge', do inform my search to overcome the human-machine dualism.

2.1.1 Boundaries – Agency – Complexity – Knowledge

> *"A cyborg exists when two kinds of boundaries are simultaneously problematic: (1) that between animals (or other organisms) and humans and (2) that between self-controlled, self-governing machines (automatons) and organisms, especially humans (models of autonomy)."*
>
> Haraway in Gray 1995: 1

Haraway's definition of cyborgs stresses the key theme of cyborg studies: problematic boundaries.[46] As is apparent in the discussion of Haraway's challenging of dualism, the blurred **boundaries** between human and machine are linked to a stepping away from the human-centred approach.

Not only humans have **agency**, technology has too. Cyborg studies investigate how technologies participate as agents in producing social life and subjectivities, or in this case: modalities of embodiment. Machines, more concretely insulin pumps, have agency? I am not sure how I feel about that. It does not fit with my passion for individual consciousness and agency; my focus on people making sense of their lives and illness and playing an active part in it. In my account I opt for giving more weight to selves and their meaning making processes than to the societal or cultural anonymous forces that inform but not determine them. And would I now say that a lifeless, consciousless machine also has agency? What about intentionality, my main argument for embodiment, machines do not have that, so do they have a different type of agency?

---

[45] "Like a fish taking a small quantity of water along with him to live on land. The bubble all too easily bursts. [...Instead] The cyborg deliberately incorporates exogenous components extending the self-regulatory control function of the organism in order to adapt to its new environments, automatically and unconsciously, leaving man free to explore, to create, to think and to feel" (Clynes and Kline (1960) *Cyborgs and Space*: 29, in Haraway 1995, XV).

[46] Downey defines cyborg anthropology as studying the relations among "knowledge production, technological production and subject production" (1995: 341). Thus technology, human and knowledge.

While I cannot solve the conundrum, and can thus be seen as being inconsistent, I do embrace this technology-with-agency approach, as it helped me to interpret the ethnography. Seeing the pump as having 'some kind of' agency, allowed me to look at what the pump 'does' in all this, instead of merely looking at what people thought of it and did with it. In the analysis I 'solve' the conundrum by saying that technologies shape our modalities of embodiment —how much agency is involved in 'shaping' is open. Perhaps a more appropriate way to describe the agency of machines is that they "acquire and redistribute human agency within society" (Downey 1995: 364).

In seeing technology (and its agency) not as an autonomous force but rather as a social product I follow social science author Downey. He describes how sociologists of technology achieved this move: they conceptualised the content of technology as a product of social judgment and the artefacts as participants-with-agency in the field of social action (actor-network analysis) (Downey 1995: 365). Opening up the fixed categories of human and machine, blurring the boundaries, allows for more dynamic views on the relationships between the two (or composite one). While cyber culture (the omnipresence of technologies) can be seen as imposing ever more control (in Foucauldian style) over society and individuals, at the same time, since the organic and the technological are not necessarily opposed to each other, it can be seen as offering new possibilities, new configurations between humans, nature and machines.[47] More technology does not necessarily mean a reduction of humanity, it can also enable us, make us 'super'human. Leaving behind the human-machine dualism, means diving into a 3-dimensional continuously changing sphere. This jump on its own, while daunting, is already enabling.[48]

Stepping away from two clearly distinct categories in opposition to each other, means embracing **complexity**. This move allows for 'ontological softening' "the erosion of distinctions between categories and realities that were previously taken to be stable and discrete" (Law and Moser 2001: 3203). It allows for the ambiguity, dynamics and rich gamut of our relations with technology, centring on issues of control, identity and boundaries. These are continuously redrawn and reconfigured. I refer to Gray

[47] See for example Escobar (1994) and Downey, Dumit & Williams 1995.

[48] Concretely, it allowed me a more encompassing take on the ethnography, instead of trying to force things into the tight corset of 'a human acts with and through a machine', with the latter remaining a separate entity.

(1995: 2), who lists that cyborg technologies can be either restorative —restore lost functions, replace lost organs, or normalizing —restore some creature to indistinguishable normality, or reconfiguring —creating post-human creatures and enhancing and probably several of the above at the same time. Understanding how young people live with their insulin pumps is helped by an approach that allows for more complexity than the constricting human-machine dualism.

I illustrate with two fascinating ethnographic studies that relate the complexity and ambiguity in the encounter human-machine. In *Embodied Progress* (1997) Sarah Franklin focuses on how the experience of women undergoing IVF treatment is lived and embodied. Women talk about 'living IVF' as it is a way of life and the technique takes over their lives. Franklin states how ironic it is that the procedure is named after a tiny part in the whole process, the technological part, which happens outside the women's bodies. The women talk about both the physical and emotional demands of IVF, calling the process an 'obstacle course' with its pain, need for timing, need to manage their bodies through complicated routines and the continuous risk that things go wrong. Franklin shows how a technology (IVF) can shift a woman's perceptions of herself and make her re-evaluate who she is and what she wants. Similarly, in '*Real-time fetus*' Rayna Rapp (1997) describes how pregnant women interpret ultrasound examinations. Rapp discusses in detail the powerful impact of sonographic imaging on women's embodied knowledge and experience. The imaging is experienced as limiting, since it bypasses the women's embodied knowledge of their baby: visual signs replace embodied states, and by the 'window' in the belly the baby is made into a social fetus. At the same time, though, the imaging is experienced as enabling, the women can decide to do tests, can get their partner more involved and their own bond with their baby as a person develops. Both Franklin and Rapp start from embodied experiences to analyse the relation with technology, giving a colourful rendition of lived ambiguities in relation with technology.

Complexity means to emphasize partiality, as Escobar says: "to abandon any pretense at general laws or objective accounts" (Escobar 1994: 222). "My hope is that cyborgs relate difference by partial connection rather than antagonistic opposition, functional regulation or mystic function." Here Strathern quotes Haraway (Strathern 1991: 37). Though not a 'cyborg anthropologist' as such, but a cultural anthropologist

and techno-science author, Strathern also refutes dualisms. She sees technology as putting an end to the cultural metaphor of the body-machine dualism.[49]

> "This particular pair (body-machine) were formerly connected and contrasted by analogy, in that they provided metaphors for different aspects of human nature. It is their metaphorical status that now seems subject to encroachment. Technology literally helps 'life' to 'work'. (...) Yet insofar as they cannot evoke distinctive domains of life, bodies and machines can no longer serve as metaphors for one another. It follows that the relation between them will become a poor analogy for contrasting what is given in the world and what is artificial, the basis upon which the anthropological concept of culture has rested throughout the twentieth century" (Strathern 1992: 60).

Strathern coined the concept of 'mutual inclusion': the idea that things are not necessarily opposed to each other, the other may be incorporated without being assimilated (Strathern 1991: 35). She states that we should see unity or plurality in an ambiguous way: "One is too few but two are too many" (Ibid.: 36).[50]

Neither Haraway nor Strathern see science as factual but instead approach it as a cultural knowledge practice, to be studied as any other.[51] Sarah Franklin (1995: 173) mentions how they both expand "what it is to 'know', such that knowing is inseparable from being, imagining or desiring". Indissolubly linked to the creation of **knowledge** and knowledge practices is the issue of agency. I refer back to Haraway at the start of this chapter, refuting appropriation and domination of what is known by the knower: "(In the analytic tradition) an object of knowledge is finally itself only matter for the seminal power, the act, of the knower (...) but any status as *agent* in the productions of knowledge must be denied the object. It —the world— must (...) be objectified as a thing, not as an agent" (Haraway 1991: 198). Instead she pleads for 'situated knowledges' (that) "require that the object of knowledge be pictured as an actor and agent, not a screen or a ground or a resource (...) [T]he world encountered in

---

[49] "A distinction between machine and body has for long held that between the artificial and the natural. Technology does not sustain the same distinction at all" (Strathern 1992: 47).
[50] Which Mol (2002: 82) rephrases as "More than one and less than many".
[51] Franklin (1995: 173) "(Both) exemplify a cultural hermeneutics of knowledge practices that foregrounds the constitutive role of metaphor, analogy, classification, narrative and genealogy in the production of natural facts."

knowledge projects is an active entity" (Ibid.: 199). [52] Activating the formerly passive objects of knowledge reminds us we are not in charge of the world and foregrounds knowledge as a "situated conversation". "We just live here and try to strike up non-innocent conversations" (Ibid.: 200). Strathern and Haraway draw our attention to the dynamics in knowledge, showing how things are fluid and in constant reconfiguration.[53]

This focus on practices and putting the agency (and knowledge generation) in objects brings me to the technology-in-practice approach of science and technology studies and will lead me to philosopher Annemarie Mol, who sees knowledge not as residing purely in people's minds but instead in organisms, objects and practices.

2.2 Technology-in-Practice — Science and Technology Studies (STS)

Technology-in-practice is the more recent (1990's) of three theoretical perspectives in sociological studies on medical technology.[54] This view holds the middle ground between two essentialistic perspectives: technological determinism and social essentialism. Technological determinism sees technology as the driving force that shapes social relationships (Timmermans 2003: 97). It originates from a humanist concern with the dangers of technology and sees technology as purely to the disadvantage of the patient (for example, leading to more control and alienation in patient-health carer relationships). Social essentialism takes the opposite side of the spectrum, seeing medical technologies as neutral entities that are put to use and interpreted in social interactions. Technology-in-practice is a more dynamic approach and studies the dialectical relationship between technology and its users. **It looks at what technologies 'do'**. Technologies are one actor among many, in continuously changing configurations. To illustrate what this means concretely, I mention two interesting studies of technology-in-practice. [55] Analysing the usage of the metered dose inhaler (asthma) Alan Prout (1996) uses actor-network theory to show the potential of a

[52] Based on the agency of the world in knowledge practices, Haraway goes into the interesting direction of seeing the world as a Coyote or trickster, allowing us to include the sense of humour of the world (Haraway 1991: 199).
[53] About bodies as objects of knowledge Haraway (Ibid.: 201) states: "[t]heir *boundaries* materialize in social interaction. Boundaries are drawn by mapping practices; 'objects' do not pre-exist as such."
[54] I follow Stefan Timmermans' clear overview in Timmermans (2001) and Timmermans & Berg (2003).

non-dualistic approach towards medical technology. Instead of positing society and technology as two distinct entities, actor network theory allows Prout to focus on performative interaction of both human beings and technologies. Thus Prout suggests that the inhaler does not merely have an impact on social relations, instead he shows how in using the inhaler children are engaged in a process in which "technologies and people mutually constitute each other" (Prout 1996: 200). Also studying asthma, Dick Willems (1998) suggests how different drugs, engaged in different practices, create different diseases. He illustrates this with two patients who both have asthma, though by taking different drugs that act in different ways, they engage in different practices. In the process their lungs are 'mapped' in a different way. Airways are treated as different airways by different drugs: some strengthen entrance barriers, some open up tubes while others treat inflamed membranes. Willems stresses how drugs and devices do not act in isolation but always as parts of a network.

While actor-network literature lies at the base of the technology-in-practice approach (cf. Latour 1987), it has moved on over the last 20 years (cf. Law & Hassard 1999 *Actor Network Theory and After*). Science sociologist John Law (1999) is a main player in this move 'after' actor-network theory. While 'networks' allow us to talk about relationality, Law sees three major flaws with them. I skip over his critique of networks being 'hegemonic' (part of the established way of representing the world and thus uncritical) and 'performative' (thus using 'networks' as an analytical tool regurgitates the way in which the world is already made), to look at his third objection: that networks are functional. Studies focusing on networks sketch a functional relationship between entities. "All that is solid —human and non-human— melts into air in the face of the need to create a coherent, ordering and functioning actor" (Law n.d. 'Networks, relations, cyborgs': 6). Instead Law looks for a non-foundational (refusing a priori categories) relational analysis that avoids falling into functionalism. He mentions how Haraway with the hybrid cyborg concept successfully avoids functionalism by not combining the different things into a single frame, but rather allowing for a split vision, multiplicity: more than one but less than many.[56] Against

[55] See also Berg & Mol (1998) *Differences in Medicine. Unravelling practices, techniques and bodies* for a fascinating collection of articles focusing on practices.
[56] As mentioned before, see Strathern (1992: 35-36).

'systems', 'networks' and 'coherence', Law posits 'fluidity' 'mobility', 'partiality'.[57] The appeal of this approach is that it allows to see *what is happening*, without things having to fit (or fail) in a coherent system governed by rules. Thus when a person or an object 'fails' (not performing as it should for a system to work) this is not a failure; instead it is a reality that can be observed in its own right (not under some functional logic).

I feel this approach opens up the scene. If (especially when talking about interaction with technology) we leave the corset of 'how things work together towards a goal' (the need for coherence) we can see other things so far overlooked because they did not fit. In the writings by Law and his science and technology colleagues I found ample inspiration to approach the young people with insulin pumps.[58] I am most enthusiastic about the performative approach towards technologies.

2.2.1 The Performative Approach

Whereas the classic idea of performance sees people perform (surrounded by objects), these authors view both people, technologies and objects as actively involved in the performance. The crucial innovation is not only to see technologies as enacted, but to realize that they could have been enacted in other ways. While Law and Singleton's (2000) point is to illustrate how our stories (studies) about technologies form part of the way technologies are performed, and thus create them, here I leave that political argument aside, to instead follow their analysis of what it means for a technology (or anything) to *work*.

Rejecting the idea that technological devices work in a single way (or otherwise fail), opens up the field of how it is that things work at all. While the standard approach to technology is 'as long as it works all is fine, when it fails we will locate the fault', in contrast these authors stress the invisible work it takes to keep technologies working. I found this approach very useful, as it allowed us to look at the little things that would

[57] I recall artist Eduardo Paolozzi, famous for mapping the combination human-technology, on his discovery of the process of collage in 1946: "My anxiety and the anguish in '46 was resolved by this magic process of picture making, of introducing strange fellows to each other in hostile landscapes (...) Unlike the world of school where the universe was systematized in a certain order, the reassembly of this disparate material reflected a true state, both autobiographic and dynamic" (Paolozzi exhibition at The Dean Gallery, Edinburgh, Scotland).

otherwise pass unnoticed, at what needs to be in place for something, in this case the insulin pump, to work.[59] A concrete example illustrates. Relating the story of collecting hay bales, Singleton draws our attention to the skill of the tractor diver, the co-operation of the family in the field, the good weather etc., to show the *specificity* of the hay making performance. Collecting hay is different from day to day (the weather, different workers, different tractor). Multiple performances lead to different ways of working. Even when abstracting the social part, merely the technological side of working of for example the tractor is a sequence of different performances. As Singleton mentions: does the engine run smoothly, will it make strange noises, will it go into gear, will the tools respond? "The mechanic isn't confronted with a working (or non-working) tractor as a single entity. It's a multiplicity, a set of different and no-doubt interacting performances" (Law.and Singleton 2000: 5).

2.2.2 Multiplicity and Practices

The most inspiring author in this performative approach I find to be empirical philosopher and medical anthropologist Annemarie Mol. In *The body multiple: ontology in medical practice* (2002), Mol describes the multiple atheroscleroses she encountered during four years of ethnographic research in a Dutch hospital. She makes a bold ontological move, instead of seeing different versions of the same disease, she states that they are actually multiple diseases, just like there are multiple bodies, legs and doctors. She arrives at this multiplicity by a focus on practices. To summarize her position in one phrase: multiple performances lead to multiple realities. In her book Mol investigates ethnographically how these multiple realities hang together. Multiple realities? Multiple as opposed to the singular reality in perspectivalism, where objects are the points of focus of different people's perspectives. For Mol the problem with perspectivalism is that by positing the body and disease as the one physical reality, studied by biomedicine, it leaves only the *perspectives* of doctors and patients as study topic for social scientists. To overcome being limited to talk only about ideas and

---

[58] Law and colleagues are all linked to the Centre for Science Studies, Department of Sociology, at Lancaster University.

[59] Another example, maybe more appropriate in this context is that of the Zimbabwe bush pump, in a study by de Laet and Mol (2000). The reason the new water pump quickly becomes a success in villages all over Zimbabwe lies in the 'fluidity' of the pump. Bits can fall off, be added and changed, there is not one right way for the pump to work. In different villages the pump looks and works differently. The fluidity of the pump stretches even to what counts as 'working'. The pump 'works' when it produces clean water, but what is clean water? Even if the water by the pump does not meet the official standards the pump does not necessarily fail (Law & Mol n.d.: 4).

meanings, and to get back to the physical body and disease, Mol looks at practices. "Ontology is not given in the order of things, but ontologies are brought into being in common practices" (Mol 2002: 6). The body is no longer a passive object waiting to be seen from different perspectives, but comes into being, and disappears, in practices. As the object differs between practices, reality multiplies (Ibid.: 4). Mol studies the practices in which atherosclerosis is enacted: consultations with doctors and patients, operations by surgeons, dissection by pathologists. In all practices atherosclerosis is defined differently, however all know what is meant by 'atherosclerosis'. It hangs together. How? The relation between objects is enacted in practices. Mol gives an example that overcomes the mind-body dualism: a corpse in the morgue does not become a person by adding life to it, but by taking away and putting back again a piece of cloth.

Reviewing the literature on the topic, Mol finds theories on 'systems', 'discourses', paradigms' or 'culture' not appropriate as they all hold the image of an organism as a model for what it is to hang together.[60] Her point is not about coherence as in one whole, but rather about connectedness. It is about seeing unity in an *ambiguous* way. Mol finds inspiration in Strathern's critique to the image of fragmentation in theories of culture: a fragment (wrongly) suggests that once there was a whole. Also Strathern's concept of 'partial connections' is useful. Strathern gives the example of a feminist anthropologist scholar: they are not two different persons, or one person divided into two, but are partially connected: more than one, less than many (Strathern 1991: 35 in Mol 2002: 82). Mol's point is about the co-existence of what is different, of holding what is other inside the self. The idea that differences are not exclusive, that the other can be incorporated in the self (incorporated without being assimilated), she finds again in Strathern's work: the concept of *mutual inclusion.*[61] To understand mutual inclusion we have to leave Euclidean space, where things have scale and location. Concretely in Mol's ethnography —which she calls 'praxiography' as it studies practices, the way reality is enacted— this gets complicated. For example it

---

[60] She rejects the homogenizing 'network' (Latour), to then discuss theories that focus on co-ordination, allowing for multiplicity in different ways: social worlds (e.g. Anselm Strauss), versions of the world (e.g. Goodman), the frame, and finally modes of ordering (e.g. John Law), throughout which she sees a move towards an increasing decentring of the subject (Mol 2002: 64- 69).

[61] She also mentions author Michel Serres who suggests to instead of thinking of objects like boxes related in a transitive way (one bigger than, containing the other), to think of them like bags, related in an intransitive way (one may contain the other and vice versa) (Mol 2002: 144). Strathern's example of how a son contained in, may also contain, the father (Mol 2002: 147).

means that it is not the artery in the leg of the patient. Instead they exist alongside each other.

> " An artery operated on is not necessarily smaller than the patient operated, nor is the first situated inside the latter. The artery may be bigger in that it receives more attention during the operation than the patient. And the patient does not contain the artery; he or she is not the body on the operating table plus something extra (a mind, a social life). Instead the patient is someone whom, at some other moment, the surgeon may exchange jokes with, (...) who, elsewhere, may have a wife waiting for a telephone call. The two realities, that of the artery and of the patient do not encompass each other: they are situated side-by-side" (Mol 2002: 149).

Though I find it hard (impossible) to logically/ ontologically make sense of this approach, at the same time it itself makes sense. It makes sense of our conflicting existence. 'At another moment', 'elsewhere': time and place become situation. Moreover, one thing can be many things at the same 'time' without conflict, as it is not a singular but multiple thing. It also makes sense of our experience or strategic practice of mind-body dualism without supporting the dualism.

To sum up, I appreciate Mol's approach because it is dualism-free.[62] Dualisms are avoided from the start by the philosophical stance of seeing ontologies as 'brought into being in practices'. Mind-body, human-machine (my main concerns here) but also subject-object, culture-nature: none exist, since shifting practices are the 'entity'. The next move is made by seeing things as hanging together in mutual inclusion: so even difference (and otherness) are incorporated in the self. I point out some interesting implications of this approach.

It stresses **co-operation**: Take for example the clinic consultation. Where a focus on doctor and patient —two fixed entities with their own perspectives— outlines similarities and differences, a focus on practices shows collaboration: it takes a doctor and a patient (and a room, chairs, files etc) to perform a consultation. Looking at 'who does the doing' also allows us to look at who and what are involved in a practice: people, settings, objects, technologies. It makes us realize what it takes for something to work.

---

[62] Though they *do* exist, in peoples' minds and life-worlds. And thus earlier I mentioned I somehow resigned to the mind-body dualism (as not desirable to avoid it completely).

Her approach stresses **practices**. Amidst the abundance of approaches in medical anthropology centring on narrative, health beliefs, ideas and interpretations, it is refreshing to find an approach that looks at what *happens*. Medical professionals can too easily dismiss the qualitative approach as 'only stories', and find truth and reality only in quantitative approaches. Mol, by not criticizing either quantitative or qualitative studies, but by offering an entirely new approach, makes a strong point in this stale battle.[63] Through an ethnographic case study she shows doctors that social scientists can talk about an illness that is material and active. Disease is something that is being done. It is not just a matter of reflecting. Mol goes even further, by locating *knowledge* in practices. Knowledge is not in peoples' (patients', doctors') heads, but is spread over instruments, technologies, buildings, objects, people, and it is enacted in practices. Thus also in knowledge, any dualism and power discrepancy between doctors and patients is avoided. "It may be a good methodological strategy to withhold from doctors and patients the subjectivity we are reluctant to grant corpses in order to analyse *embedded knowledge* instead" (Ibid.: 50).

3. Embodied Knowledge – Embedded Knowledge

Though only three letters apart, embodied knowledge is very different from embedded knowledge. Or is it? What seemed a good idea at the start of this chapter, to structure the theories around mind-body (phenomenology) and human-machine (cyborgs and practices), has put me into trouble. For how do I combine phenomenology (embodied knowledge) with performance theory (embedded knowledge)? I explain my pragmatic solution.[64]

---

[63] In her words, she does not criticise the foundational approach of biomedicine (the fact it deals with the physical body and disease and that social sciences can merely talk about ideas about it), because that would merely strengthen their position (by saying it is wrong you state their position so many times as a fact). Instead she doubts its very foundation: "Is pathology indeed foundational if we no longer investigate medicine as if there are knowing subjects on the one hand (pathologists, doctors) and objects to be known (bodies) on the other?" (Mol 2002: 48). This fits with her reference to Foucault who argued for "noncritical strategies for escaping dominant ways of thinking"(Ibid.: 47). Idem Rapport (2003: 16) as mentioned before in the Introduction.

[64] My approach to the ethnography (both methodology and writing) is entirely informed by a phenomenological approach. I only encountered the 'practices' approach further on in the process, when looking for inspiration to analyse the technology part of the research. However, I would like to ask the reader to keep the 'practices' and fluidity of mutual inclusion in mind when reading the ethnography.

In the first part of this chapter I explained extensively how the phenomenological tradition informed my approach towards fieldwork and ethnography. It coincided with my view of human beings as conscious and sense-making individuals. The concept of embodiment allowed me to start from people, showing their interaction with each other and their world and in a more intimate sense, their body and illness. It also was a way to bring in experience instead of mere representation. People are the start and endpoint.

Then came technology, in the shape of the pump. Focusing merely on people could now, with a non-human actor in play, lead to a division and opposition[65], a one way traffic: people making sense of and relating to this machine, with the pump an inactive object to be made sense of.[66] I would lose the dynamics I liked of the phenomenological approach. The pump was a lazy object waiting to be made sense of. I found a way around this in cyborg studies and the 'performance', 'technology in action' approach of science and technology studies. They allowed me to see more at play than merely people interpreting technology. By seeing boundaries not as solid but moving, and combinations of people and technology as challenging hybrids. Technologies also acted, or at least were enacted, and were part of shifting configurations between them, people and objects. These performances were not situated in one coherent logical system, instead there was multiplicity: multiple performances, objects, persons, technologies and friction between them: multiple realities. Knowledge was not only a mental activity but also being and doing (Strathern, Haraway) and the activity of knowing was not only situated in peoples' heads but spread over —and realized in enactment between— people, objects and technology: knowledge was performed in practices.

Then I do (pragmatically) manage to combine the two approaches. Since what I take from phenomenology coincides with what I take from science and technology studies: relatedness, movement, interaction, people geared towards the world and the world geared towards them.

---

[65] Even though this is an opposition people make, I did not want it to be the overarching framework for my approach to this topic.

[66] With this I do not mean that everything in a relationship should be commensurate, of the same kind, nor that a relationship should be balanced. What I aim to stress is to see dual or multidirectional traffic, which can be unequal etc.

There is only one problem: 'agency' —though it might be 'intentionality' or even 'consciousness'— as they all point to what is to me the crucial difference between humans and machines. Merleau-Ponty centres his phenomenology on the mystery of what is typical of our human relation to/in the world: our intentionality, the fact that we as bodily beings are geared towards the world. Philosopher Charles Taylor (1985: 24-27), calls man a self-interpreting animal, "to be a living agent is to experience one's situation in terms of certain meaning". In my view, technologies do not have intentionality or consciousness. But do they have agency? That is, if there is such agency that is unconscious and unintentional.[67] Perhaps 'agency' is a wrong term. 'Enablement' may be more appropriate, as technologies enable things to happen.[68] Technologies have agency in that they are enacted, performed and thus shape people's worlds.

This brings me into the quagmire of the human-machine dualism that I said I wanted to bypass. Again I need a caveat here: bypass only in a certain sense, in a sense that allows more focus on what machines 'do', their impact, the combination of people and settings that come together for machines to 'work'. Of course machines are different from humans, thus I reject any radical symmetry between humans and non-humans. Without wanting to get entangled in the sticky web of human-machine relations, a longstanding topic in science and technology studies,[69] I clarify my stance with a concrete example. Taking a 'performative' approach to an organizational setting, Law and Moser describe Andrew-the-manager of the company as a cyborg, part human, part machine. They explain that he is "materially heterogeneous, a set of extensions and prostheses, fleshy and otherwise" (Law & Moser 2001: 4). They reject Goffman's division between people and props, who insists that it is people who act rather than objects, to instead stress that this division does not hold and that props perform as well.[70] Like Goffman, I do not accept symmetry between people and objects, people

[67] The agency of the young people 'living' and 'doing' diabetes and pumps is a key theme in this work, the approach to care, empowerment and responsibility centres on it. This agency I take as conscious and filled with intentionality, creativity and imagination.

[68] Another term, suggested by Rapport (personal communication), could be 'consequentiality': as the use of technologies has consequences.

[69] For example, I am not sure whether they take the symmetry between humans and non-humans merely as theory rather than reality. Alan Prout mentions how the radical symmetry between human and non-human actors of actor network theory is contested and Law's defence of this that symmetry is an analytical rather than a moral practice (Prout 1996: 215).

[70] Goffman 1971. *The presentation of self in everyday life*. Harmondsworth: Penguin.

are very different, for example, people can decide not to use a machine, to throw it away, to change it.

I find theoretical inspiration for this in the work of science anthropologist Lucy Suchman.[71] In her article *Human/Machine Reconsidered* (n.d.), she investigates what it means to say that humans and artefacts are *mutually constituted.* She stresses that in this ongoing process persons and artefacts do *not* constitute each other in the same way, she gives the example of the form of agency that grants 'actor status' (only humans can do this). Hence she argues for a restoration of the boundaries, re-introducing the difference between humans and machines, in order to "restore authorship and thereby accountability to our relations with artefacts" (Suchman n.d.: 7). This fits with my stress on people's (health carers', patients', families') responsibility both in managing diabetes and in using insulin pumps. One of the dangers of symmetry between human and machine is that it seems merely to describe things as they are, without allowing for change or improvement. When dealing with people and their health, merely a description of mutual interaction between humans and machines does not allow for addressing problems and seeing solutions, how things would work 'better' together, for example, how a person could get more benefit out of a certain medical technology. A focus on interactivity and performance (STS) (casting aside concepts like failure and 'working better', but merely looking at all that is at play) does not allow space to address such issues as power imbalances, misuse, guidelines to use a technology for better results. It does not allow us to give a full account of (and space for) the people involved, and the lives they could lead. In other words, my problem with the fluidity and symmetry of some STS is the relativity: it does not allow us to put the 'person' central, nor one aspect of the person, for example his/her health. Something which in this work I do, in line with my essentialistic approach to young people: they are one biophysical body for their whole life. To me, the urgency of this topic would make a neutral, hands-off approach irresponsible and immoral.

Suchman (Ibid: 5) concludes that: "[A]gency —and associated accountabilities— reside neither in us nor in our artefacts, but in our **intra-actions**". I could not agree more when she says that the problem with agency (and the ensuing

[71] Suchman, a colleague of John Law at the Department of Sociology at Lancaster University, did innovative research on machine-user interface and is reputed to have proposed the green start button on the Xerox machine.

problems with locating it in human / non-human relations), is that we usually talk about it as if it presupposes a field of "discrete, self-standing individuals".[72] Perhaps then, following Suchman, '**intra-action**' is a better term to discuss human-machine relations —as intra-action, unlike agency, does not reside in one distinguished entity, interaction unfolds. I would reserve the term 'agency' uniquely for people, to safeguard consciousness, intentionality and creativity, as these are what makes us who we are and aware that we are, (an anthropological account would not be one without these human qualities), however, without seeing people as independent individuals, rather as Strathern phrases 'dividuals', as who we are is always shaped in relation to others and in a social, cultural, environmental context.

And embodied knowledge versus embedded knowledge? A person, his/her embodied, lived experience and knowledge, is in continuous interaction with his/her surroundings. The embodied knowledge of phenomenology, generated through and residing in people's bodies, is opened up to include 'knowledge' embedded and enacted in events, practices, objects, people. Perhaps a term that combines both is Haraway's 'situated knowledges', including context, practices, the specificity of changing configuration and fluidity. I also find it in Merleau-Ponty's point that "the body's spatiality is one of situation not of locality" (Hammond: 162).

Concretely then, in analysing young people's relations with the pump (Chapter 8), I will mainly be guided by Michael Jackson's and Drew Leder's phenomenology of human-machine relations that starts from embodied experiences. Acknowledging the experienced dualism without essentializing, Jackson offers an approach respecting our human, embodied experience which continuously oscillates, as our sense of being is a function of our interaction, true to Sartre's 'l'existence précéde l'essence'.[73] "[T]o see the classic antinomies of reason and emotion, body and mind, self and other, nature and culture, subject and object not as competing ontologies, but as terms we deploy, variously and often interchangeably, to capture different modalities or moments of intersubjective experience" (2002b: 341). Is perhaps the only difference with Mol —

[72] "Modernist epistemologies (...) treat agency as something both independent of and contained within singular entities (...) a tradition that treats separation and autonomy, rather than relatedness, as the mark of humanity" (Suchman n.d.: 5). This again recalls Baier's philosophy of care, as mentioned in chapter 5 and in the conclusion.

"ontologies are brought into being in common practices" (Mol 2002: 6)— then that existentialist and phenomenologist Jackson puts the person and the person's experience central, putting inter*subject*ivity in the place of mere interaction?

At this inconclusive —though (because?) more informed— point, it is time to leave the literature and dive back into the ethnography again. A technological device has arrived in the familiar setting of the Millness diabetes scene.

***

[73] Jackson: "... for experience is continually oscillating between quite various senses of self and other depending on the context and character of the interaction" (2002b: 341).

7

Millness Health Carers and Pump Therapy

The main aim of the Millness paediatric diabetes team caring for adolescents is to keep the young people coming, to not scare them away by a demanding management routine, or by telling them what to do. Behind this 'non patronizing' credo lies the idea of empowerment. Although this may not be the correct word, as Sally says: "Dr. John does not like the word empowerment, it puts too much onus on the young person". As *empowerment* is a fashionable word in health care today, with many possible interpretations and ensuing misunderstandings, I should use a different term. What informs Millness health carers in their adolescent policy is granting the adolescents *autonomy* and *independence*. Treating them not as children, but as decision makers, as people with a right to choose. Also as people who have a right to enjoy life and normality, two things the health carers deem extremely important at that age.

Enter the Pump. A new treatment, a different way of administering insulin to the body. Instead of injecting a prefixed dose of insulin in yourself 2-3-4 times a day with an insulin pen, you continuously wear a pump connected to your belly. This device gives you a small amount of insulin every three minutes, which with the push of a button you top up with extra insulin at meal times.

Does this pump make a change? Of course, since any object, activity or idea does not go unnoticed. Let me rephrase the question: *which* changes come along with the use of the pump? At the same time, let me specify the question: which changes come along in the way *doctors* approach and 'do' diabetes —a new treatment opens up possibility of new treatment standards and goals?— and in the way *young people* manage and live diabetes.

The next two chapters (7 & 8) focus on the effect of the new actor pump on the familiar setting. We listen to health carers, young people and their parents talking about the pump and we observe their practices and concomitant sense making.

1. The Paediatric Team

A meeting of the Millness paediatric diabetes team on pump therapy. Paediatricians and nurses discuss the design of a new research project and what conditions should accompany the pump therapy. [*I am surprised, this meeting takes place after eight young people have been living on pumps for a period of one year. Pumps, I have read and have been told, demand extra management and care, in order to benefit from them but also more pressingly, to avoid possible lethal risks. Surely the team must have discussed these things before? However, judging from the conversation, it seems this is one of the first discussions on conditions (such as management routines, goals, to go with pump therapy). I can only assume this springs from the fact that so far pump implementation was a prototype.*]

The main discussants are John, head paediatrician diabetologist of the team and Sheila, diabetes specialist nurse who from the start has been in charge of all pump patients. While Dr. John sees the pump patients in clinic consultations, Sheila is their nurse and point of contact at home. The rest of the team know little about pumps, as there are only eight young people on pumps out of a total clinic population of 500.

Sheila gives the team an overview of the past year: "All young people in the group have responded in a similar way. At the start they were extremely motivated, there was a reduction in their HbA1c; then, after about eight months, they became complacent, stopped blood testing and since then their HbA1c has gone up. Now I am trying to pick it up again with them, they are compliant with that. They are quite receptive now to me. I say 'we need to do some blood tests now to get the best things out of the pump'."

The team asks if she has concrete data on that.

Sheila: "I have a list of their HbA1c's prior to the pump, it then went down and after eight months, HbA1c is up again. They all stopped blood testing before that, but [*she stresses*] all are happy with the pump."

The team wonders whether this scenario is common to young people everywhere. John says he spoke to a colleague in America and it struck him that all kids that had stayed on the pump felt physically better.

John: "Are we saying pumps are less faff? 'Cause I get nervous, I am worried those kids have a needle in them. Sometimes I am watching sports on TV or last week I went to the cinema and I sit there and all of a sudden I think: what would it be like to sit here with a needle in my stomach?"

Sheila: "These kids are afraid of needles, at the start it is their biggest fear, but after that, I haven't had to assist anyone."

Anthropologist Alex asks how come the HbA1c's have gone up.[1]

John: "Partly because we are not geared towards keeping it down."

Alex concludes: "So we should write some protocol saying: 'at so many months your blood sugars will come up'."

While I am about to fall off my chair, I am happy to hear Dr. Veronica, the junior doctor who recently joined the team, and the only team member who favours intense management, protest vehemently: "No no no, don't say that..."

[*Veronica is protesting against the acceptance of the rise of the HbA1c as a natural fact: 'when on the pump, after eight months HbA1c will come up', while it is merely a consequence of patients not doing blood tests and not reacting to them. Writing it in a protocol would state it as a fact, as something to expect.*]

Sheila gives her view on the rise in HbA1c: "It's about the balance between eating and insulin."

John chips in: "What I wonder is how much of it is technological advice from us. The best example is Callum: he had good control but he blew up like a balloon by eating. But he knows the pump and how to handle it."

[*I check John on this later and he explains he means that it is not something extra the team can give the young people, but that it is more up to themselves.*]

Sheila: "What I do now in the visits, I say this is about how many units I want you to give yourself with meals, but also: if your dinner is less, give less. I am a bit more directive now."

Veronica takes her chance: "How about doing more regular CGMS (Continuous Glucose Monitoring System) testing to motivate them?"[2]

---

[1] Alex Greene, who has worked with the team before, as mentioned in the Introduction. See also Greene 2000.

Sheila is not convinced: "I'd just watch that one. It's a big faff."

[*Sheila very often uses the word faff: anything the young people would be asked to do and which is not fun, is a faff. And so you refrain from asking them.*]

Veronica insists: "Well, but that's what you want them to do, four tests a day."

John is not convinced either: "But then what happens is they all fade off like D's patients in the US who all stopped testing."

Veronica persists: "Yes, but in the DCCT (see DCCT 1995), 95% still managed to do it. They were on intensive support, which our patients will be."

Sheila phrases the team's main orientation again [*against which Veronica is carefully battling*]: "We want *them* to drive this as well. We don't want to say 'this is what we want you to do'. So now I visit them again and I ask them what do you think is missing from this? And they all know the answer. And I ask what do you think would be the advantage of doing blood testing. In the past, they've got on with it, now I'm just pulling the reigns back."

The meeting is wrapped up. The team is now aware that if in their next trial they want to prevent a rise of all pump patients' HbA1c, they need to combine the therapy with more guidelines.

This meeting took place six months after I started visiting and interviewing the eight pump patients and accompanying Sheila on home visits. Had I been a team member not involved with pump patients, I would have described the pilot pump project over the past year as follows:

> Eleven young people started pump therapy and were told to do blood tests. Their blood sugar levels went down. After 8 months all of them had become complacent and had stopped doing blood tests, as a result their HbA1c went up. Now, 12 months later, Sheila will pull the reigns again and make the patients see the point of doing blood tests and so the HbA1c will go down again. Sheila knows what she is doing and is in charge, she seems to have a good rapport with the young people, no conflict. I have confidence in the project; it has given our

[2] CGMS: Continuous Blood Glucose Monitoring System: a small plastic box-like device linked with a sensor (needle) to the belly, worn by the patient continuously for three days and night. By putting in certain blood test results the machine provides a graph of the blood sugars flow over the three days. This is very enlightening as it shows blood sugar levels at moments when the patient previously never tested,

> team, as the first paediatric team in Scotland, the chance to learn about pump therapy in young people. We have noticed a pattern of complacency and rising HbA1c and can thus conclude that it is wise to demand blood tests when on a pump. Above all, all patients are happy with the pump.

However.

I am not unfamiliar with the pump patients, I did not come fresh to this meeting. Apart from 'falling off my chair' at the pinnacle of Millness health carers' reasoning (i.e. making a consequence of lack of management into a fact to be expected, instead of being alarmed and investigating how to prevent it), I listened with amazement and disbelief to Sheila's status report and comments. I was astonished. Again. Had I been doing fieldwork in a parallel universe? Were my observation and interpretation skills so flawed? Almost nothing of what she said coincided with what I had gathered from talking to the pump users and experiencing her interactions with them. Was she convinced of the situation she was depicting, and (like the discordance between health carers and young people's opinions about clinic consultations (see before, chapters 1&2)) did I just have access to the other side and hear things patients would never tell her? Or had I at the meeting just seen public relations in action?

I do not wish to discredit a professional doing her job. The point I want to make is that in the pump project which formed the bulk of my research, the 'health carers' embodying for me 'the Millness approach towards pump therapy and implementation' and which consequently informed the major part of my observations and thoughts, mainly comes down to the practices of one person. One person who was on secondment from another hospital and thus new on the team, doing a new type of job, who had no one to confer with and no close examples to follow, as this was a pilot project in the country. The rest of the team was happy Sheila dealt with the pumps, and had the impression that the pump therapy went well. And maybe it did. Though that is not how I thought about it.

Why is that? During the initial months as I was talking to people on pumps, I grew uncomfortable. This was mainly when I noticed how relaxed and casual pump therapy was introduced (by Sheila) and practiced (by the users).

---

and thus had no idea it was at times very high or low. On this visual image decisions can be made for change in insulin dose.

Millness did not use specific selection criteria for young pump candidates, rather a spontaneous process lead to a mixture of people. Some who liked technology and had been asking for pumps themselves (2), some with good management who could take a chance with the pump (3), some, on the other hand, who did not manage so maybe the pump could make a difference (4), and finally some who head paediatrician John thought 'would be good with a pump' (3). The introduction of users to the pump usually consisted of a three-hour educational session. Groups of three patients, accompanied by their parents, were put on the pump and explained its use.[3] This was followed by a lunch in the hospital during which they practiced giving a bolus for the meal, and then they went home. Sheila would visit them at home later in the week to see how they got on. They could also always call her or the insulin pump company with questions. No conditions of use were imposed. Though Sheila told users they should do blood tests, most young people say they may have done them the first weeks but then stopped. Neither Sheila nor John harassed them about it. Daily bolusing was a matter of guessing instead of calculating, as users were not familiar with, nor instructed in, carbocounting (counting the amount of carbohydrates in the food eaten and thus knowing the necessary insulin dose). Sheila, as she kept emphasizing, did not want to be 'prescriptive' in this.

The philosophy guiding pump therapy in Millness seems to be: if users are happy with it, great, they keep wearing it, if they don't like it, they stop. If, as mentioned before, the ultimate goal in Millness is the quality of life, this policy is coherent. Perhaps (my amazement) at the lack of strategy, education, follow up, and vision, comes from the fact that this was a trial-run.

However, even in a pilot, pumps are worn by living people. Young people and their families were mostly left to fend on their own, with a new piece of technology that gives insulin that they need to be healthy and to live. What if something goes wrong? Surely there must be dos and don'ts with a pump. Being confronted with the relaxedness of both Sheila and the young people, I was not sure whether I was just being a technophobe or whether I had a reason to be alarmed. As this was the first and only pump therapy in action I knew, in the initial months I had no frame of reference. Though I did know that in the UK in the 1980s a patient had died on the pump and that that had almost stopped pump use in the UK for the next 20 years. People still die on pumps. When a pump malfunctions and stops giving insulin, the patient can get an

[3] William's private induction at home (see before) was an exception. He was on his own as there were no other pumps or candidates left.

overdose of sugar in the blood (DKA: diabetic ketoacidosis), which can be lethal. I also knew that the pump, as a type of intensive therapy, if combined with certain routines, proved extremely adept at lowering the HbA1c, one of the main goals of diabetes management in most centres.

2. Sheila, Insulin Pump Nurse

"*Our teenagers are quite blasé about it, worryingly blasé actually. They got away with it so far.*"

Sheila is telling a pump nurse in Boston about her Scottish adolescent pump patients. Dr. Veronica, Sheila and I are on a 3-day visit to a famous paediatric insulin pump therapy clinic in Boston, US, to observe and learn. During this trip I learnt as much about the Boston approach to pump therapy as about the Millness approach, as both Veronica and Sheila position themselves and the Millness clinic versus the Boston clinic.[4]

I am astonished. Of course her teenagers are 'blasé'. In her visits to pump patients I am struck by her relaxedness, how things should be fun, not a faff. She does not want to give them too much information, no specific guidelines or rules. Is she not aware of the message she gives her 'teenagers'? 'They got away with it': if anyone got away with it, surely it was her. As their pump nurse, wasn't it her responsibility if something went wrong? If the young people were never extensively told how to use this medical device, then how to expect them to use it properly? Though, 'they got away with it': does this mean she *is* aware that the pump can be dangerous? Is she worried, and will she do something about it? Is this unawareness, lack of involvement, unprofessionalism or rather another health care paradigm altogether?

I think it is the last option. I choose not to see Sheila as being uncommitted and lacking in professional care, as I might conclude thinking from my own (Belgian) health care perspective. Instead, I see Sheila as acting in another paradigm. Thus, while I

[4] In Chapter 9, I discuss the specific approach by Dr. Stuart in Boston and how it differs from Millness.

would reply 'of course the teenagers are blasé about their pump, as this is the message you as health carers give them, don't you realize?', the answer is 'no'. Rather, my reasoning is oblique, from my 'health care perspective' corner in which I see the health carer as originating the treatment and consequently the patients' approach to their illness and its management, especially when the patients are young people. Sheila does not see it like that. Instead, she sees the young people as the originators and deciders of their treatment approach and illness management —Again, I am only realizing and accepting this as I write these things down, when everything that happened over the course of two years is forcefully combined in a few days of writing it up, things seem to fall abruptly in place. I base my statement on what Sheila has told me about pump therapy and, about her buzz concept 'empowerment'.

Two months into fieldwork, I have managed to sit down with Sheila for a 15-minute chat.

Sheila tells me the pump is not for everybody: "Only for a minority of young people the pump can be a tool to gain control over diabetes, and they can get a greater understanding."

I ask her what type of people this minority consists of.

Sheila: "People who are willing to make changes in a positive way, to embrace technology. It's all about 'are you ready to change?' In young people with diabetes there is an opportunity to change. The pump at a certain time can give them control and the power to lead a normal life, empowerment, which is my favourite concept in diabetes care. But it is very few times that we hand over power to patients. We don't really empower them. The pump though can do that."

I agree with Sheila that the pump is a perfect tool to empower patients, though my interpretation of empowerment, and its wider framework, differs from Sheila's. To Sheila empowerment comes about, happens, whereas to me, it is has to be made to happen. The following conversation illustrates this.

Sheila: "Ideally if we were using a total empowerment model, we would accept all the decisions a person makes. But I think what we aim for is informed decision

making: we tell them the risk of a high HbA1c for a long time is amputation.[5] But they are 15 year olds, they are here and there, they couldn't give a fig about tomorrow, let alone a few years time."

Griet: "So, you don't tell them about complications?"

Sheila: "You cannot talk to them about what might happen in 20 years time, you *can* talk about the here and now. Try to invite them in the care process: what is important for you?"

Griet: "And if they say they don't care, because they don't care about tomorrow?"

Sheila: "Then you have to accept that. It is very difficult from a health carer's point of view, we are giving the best possible care. In the Young Adult clinic, there is a window of opportunity, you don't know when that might come, you have to try and open that window. You have to keep going back, it can take ten years. I know from experience that for years nothing happens and then suddenly it changes."

Griet: "How does this change come about, can health carers influence this?"

Sheila: "It can be a supportive partner, going to college, the family situation which gets better, a really good friend who takes an interest. The doctor can be a catalyst."

Another factor that can bring about this change is the pump.

Sheila: "The pump is the opportunity to give them control, with young people, because they have such a rebellious, chaotic time. Are they ready to take that opportunity? If they are not interested in taking insulin, they are not good candidates, it might be worse. I always say the pump is as good as the person who uses it. And you've got to want to do that. For some young people, the freedom that comes with the pump is a good trade off, but for others, because they're not interested in taking care, it does not weigh up. It is about being prepared to make that change. They might be just about to decide to make that change."

I ask how the pump can bring about that change?

Sheila: "People are actively deciding what they want to do, like what to eat, when to get

[5] What Sheila calls 'informed decision making' I would not call very informed. Does it then all come down to terms and interpretations? Unclear terminology accounts for many differences in care or in transferability of trial results across centres. During two years of fieldwork I have noticed that the majority of frequently used concepts in diabetes care like 'intensive' therapy, 'intensive' support and 'frequent' clinic visits cover different contents.

up, they can choose to eat three Mars bars…"

Thus Sheila sees the pump as a tool that can empower people, but empowerment will only happen when the right moment comes along, when the young person is ready to make the change. Health carers can try to catch the open window of opportunity, but do not play a significant part in opening it. For Sheila, empowerment through the pump comes down to the wearer being able to decide what he/she wants to eat and when to get up. So they are empowered in their life, not in the treatment of their illness. Diabetes management comes down to the young people, they are ready or not. No one can or should force them to make a change.

So far the Millness team's approach to insulin pump therapy. In Chapter 9 we will see different, I would suggest more 'committed', approaches to the pump, in a Boston and a Gothenburg paediatric clinic. But first, we look at how the Millness young people relate to their pumps.

***

8

Millness Young People and Insulin Pumps: Embodiment and Incorporation

How do young people wearing pumps live diabetes?
I could say: they live it less. I could tell you about how they use the pump as a tool to have diabetes interfere less in their lives, to do and eat what and when they want (as pump nurse Sheila promoted the pump). This would have me write about tool use and agency. Whose agency? The health carers or the wearers? Both: the health carers see the pump as a way to reduce the hassle of diabetes and promote the pump as giving back freedom; (consequently) the wearers see the pump as the bringer of freedom, allowing them to do what they want when they want it, and they eagerly hand over diabetes management to the pump, relieving them of the need to inject, test, think and remember. But the issue lies elsewhere: 'tools' and 'agency' are concepts belonging to a by now often challenged ontology. They dwell in a world where people are subjects —'agents'— and machines are objects —'tools'— that can be used by agents. Not anymore in a world after actor-network theory, with ideas on fluidity, performance, practices, multiple realities.[1] The dynamics between wearer and machine travel both ways.

Thus I aim to look at both wearers and pumps 'doing', or at least, having an effect on each other. For this I should start in the middle of things. I need to see the pump-in-action. In fact, I should see the young person-with-the-pump-in-action. This would enable me to avoid the other dualism mind-body, by keeping in mind Merleau-Ponty's stress on intentionality of our being embodied: "consciousness is not a matter of I think that but I can". And so instead of looking at how they *use* pumps —and talk about

[1] As described in Chapter 6.

agency and tools— I prefer to look at how they *do* pumps: 'pumps enacted'. I talk about embodiment.

1. Embodiment[2]

I combine phenomenological anthropologist Csordas' (2000) interpretation of embodiment as a methodological attitude demanding attention to bodiliness, with Jackson's notion of 'bodily subjectivity' (Jackson 1989).[3] Thus with embodiment I also mean the fact that we live in and through a body. We engage with the world by grace of our body. Whereas phenomenology focuses on motility and perception, moments when our body is very present to us, I also want to include those moments when the body recedes, works in a tacit mode, moments when the body is absent. For this, in section 2 of this chapter, I turn to philosopher-cum-medical doctor Drew Leder's (Leder 1992) notion of *the lived body.*

Another reason to focus on embodiment is a practical methodological one. Lacking the opportunity to live daily life with young people on pumps, to observe the pump-in-action (the pump at school, during sports, with friends,...), I could only ask them about their life with the pumps. Though keen to talk, by now they were familiar with their pump and said 'there is nothing to say', as Callum put it: "I have a pump, it works." —This in sharp contrast to conversations with adults on pumps, who only needed one question from me "tell me about life with the pump?", to embark on a two hour pump saga, coloured with emotions (fear, apprehension, panic, satisfaction), physical facts (malfunctions, bruises, accidents) and medical results (blood sugar levels).[4] Not so with these young people. I need another approach.

I decide to find out what it takes (for them) for the pump to work. In order to get some conversation, my questions soon start to centre around the difference the pump

---

[2] As mentioned before in Chapter 6, anthropologist Thomas Csordas defines embodiment as "an existential condition in which the body is the subjective source or intersubjective ground of experience" (Csordas 2000:181).

[3] Which he defines as "the meaning of a bodily action is not *given to* the action by some external agent but is *in* the action itself" Jackson (1989).

[4] A comparison between adults' and young people's experiences with insulin pumps would be another interesting avenue to take, as the few stories of adults I heard, throw light on very different modalities of embodiment, and different interaction with technology.

made to their life and their diabetes, such as their diabetes management, their activities, their diet, how they felt physically and emotionally. We even discuss the fact whether they feel they have 'more or less diabetes' with the pump. The latter to my own surprise. How can there be such a thing as 'more or less diabetes', a chronic illness you have and treat or not? I clarify. I do not wish to quantify diabetes, rather the stress lies on the degree to which diabetes is present in their lives, more precisely 'interferes' with their lives. As this is the picture of diabetes formed in my mind through conversation with the Millness health carers, who also shaped my initial picture of the pump as the appropriate treatment to solve this interference, as nurse Sheila told William: "Giving you insulin all the time, it means you can sleep in and eat what and when you want".

The difference the pump made to the young people is that they forget. They forget taking extra insulin, doing blood tests. They forget they are wearing the pump, and sometimes even that they have diabetes. I ask William (15) (who we met before) and Kathy (11) how they feel about the pump.

William: "It's like, it's there, but it isn't. If I wasn't talking to you now, I'd not think about it, I'd be doing stuff. As soon as I do my bolus I think about it and then I forget. When I first got it: I was 24 hours on a machine, the more I am used to it, I forget, only when I eat and give a bolus"

Griet: "What is the difference with injections?"

William: "When I'm on injections: I have to Remember to Take insulin with me [*he stresses the actions he needs to do, like summing up a boring list*] I am more aware. I have to Take the needles when I go out, I have to Think more, I have to Count how many I'll need. Now the insulin is just with me."

Mum: "The trouble with Willy is he is such an airhead, and he forgets his boluses, 'cause his pump has become second nature to him so he forgets he has it."

Griet: "How come you forget your bolus? You didn't forget your injections?"

William: "Because I get insulin all the time, so I don't notice it when I forget a bolus."

Griet: "You didn't forget to take your injections?"

William: "Because injections was work, and I would have to do it, and they hurt. Also if I didn't take my injections I would feel terrible."

Griet: "So the consequences, if you forget to take a bolus, aren't bad, and that makes it easier to forget?"

William: "Yes."

Griet: "What about blood sugar tests, do you forget those?"

William: "I forget a lot, I'd do them in the morning, before I get up."

Griet: "How come you remember that one?"

William: " 'cause the needle will sit on the table and I see it, so I do it."

Though Kathy is four years younger than William and their diabetes history and family situation is very different, her story about the pump is very similar. It's about not having to remember and forgetting. What does she think about the pump?

Kathy: "It's easier, I don't have to remember, to take injections."

Griet: "But you have to remember to take your boluses."

Kathy: "Yes but I sometimes forget, but then I take it later."

Griet: "Would you say your diabetes is more or less present?"

Kathy: "Less. Like, I used to have to go for ten minutes at school, to have my injection. I always had to think to take things with me."

Griet: "Would you say the pump is more or less work than injections?"

Kathy: "It's less work. It makes me forget about diabetes."

Griet: "And that means you forget to take a bolus."

Kathy: "Yes."

Griet: "You didn't forget injections when you were on 4 injections a day?"

Kathy: "No."

Griet: "How come?"

Kathy: "They were more big, everything about it, it meant injecting yourself."

Griet: "What about them did you not like?"

Kathy: "It hurts, it's difficult, it's a few times a day..."

Griet: "So actually bolusing with a pump is too easy, so you forget?"

Kathy: "Yes."

William's and Kathy's conversation tells us about the embodiment of an illness and how a technological medical device can modify this. This is what this chapter is about.

William and Kathy have a good reason to forget. Forgetting to take the bolus allows them to 'forget' they have diabetes, diabetes is now in the morning at breakfast and in the evening at dinner, during the rest of the day, out and about, they can 'forget' they have it.

Nevertheless it is puzzling.

How *can* you forget about having diabetes and having to give a bolus at mealtimes while the pump is always there to remind you visually, physically, tactually? As William says, he does not forget to do his test in the morning because the needle sits on his table, he sees it, he does it. Is that not so with the pump? He wears it, he feels it, he sees it? Or not? What happens with the pump that this is not the case?

First let me mention my third reason to focus on embodiment: as another methodological device. Because I do not wish to take this talk about 'forgetting' as another throw back to the mind-body dualism. —Though it was tempting to take this embodiment again as 'talking about the experience of an illness', and again, as in other medical anthropology studies, it would be 'mind over matter': making sense of an illness, under the guise of embodiment: how we 'feel' about something.
As I think more is happening here, of a different order. Thus, in a last attempt to get something more out of our conversations, I decide to wear an insulin pump myself.

I start from my personal embodied experience to arrive at the young diabetic patients'. I will share my own surprise, frustrations and worries about the pump with Callum, John and Sara. They will talk, put me straight and say how instead it is for them.
Now there *is* something to say.[5]

[5] We will talk about practices, daily irritations, mishaps and funny episodes.

Excerpts from my field diary:

Monday

Today is P-day, as nurse Mary calls the day patients are put on the pump. My P-day. The table is spread with pump equipment: user manuals, canulas, tubes, plasters, syringes and vials, all wrapped in sterile plastic. We go straight into the workings of the pump. I hold the small box in both hands, push the buttons and focus on the display screen. In an instant the room shrinks to a 3 by 4 cm frame. From a sociable person interacting with the nurse and friend in the room, I am now a head bend down Game boy addict. I still hear Mary's voice but even that moves to the background when the screen does not react to the buttons I push. I am talking to liquid crystals 'ach' 'hey' 'oops'. Mary talks me through the main functions. "You push the Select button on the front to get new menus and you move around by the H (hour) and M (minutes) buttons on top. These two buttons double function as + (up, more) and – (down, less)". I program a 24-hour basal rate in the pump: I instruct the pump to give me a certain dose of insulin every hour of the 24-hour clock, so: 12pm-1pm: 0.5; 1pm-2pm: 0.4. This combination is saved in the memory but I can change and reprogram it at any time, when I notice that at certain times of the day I need less or more basal insulin. This basal hourly rate will be administered in tiny doses every three minutes, so every three minutes between 12 and 1 am I will get a 20th of 0.5 ml insulin, in my case, saline solution. Usually 50 % of the daily total of insulin is given as hourly basal rate. The other 50% is administered at the time of food consumption, in the form of a 'bolus', given by pushing the bolus button as many times as units of insulin are needed to cover what one ate for lunch. I learn to lock and unlock the pump, by pushing all three buttons together. I put the pump in Stop mode by keeping the 'H' and 'M' button pushed down together for three seconds, I hear three short beeps and one long one, the pump is in Stop mode. It needs to be in Stop mode when I want to program it. To give a bolus the pump has to be in Run mode: select the number of units (by pushing 'H' button), wait eight seconds and the pump delivers the bolus. I am overwhelmed — I don't know if I will ever manage this. And I have not even attached the pump. First I have to prepare the pump cartridge: I fill it with insulin (saline solution) from a vial, which I have to draw up through a syringe. I drop the syringe three times, spray half a vial over the table, the booklets and still I do not manage to fill the cartridge or get the air bubbles out. In the end Mary does it for me. I admire teenagers filling their cartridges once a week, it is a skill. Now without further ado, I can attach the pump. I opt for the

Silhouette insertion method. A plaster with a longer needle inside a tube, once inserted the needle is pulled out and discarded, the tube stays inside. It hurts, sticking a needle into you, slowly, all the way down. I click the pump on the tube, put it in Run mode. I proudly leave the room. In the hospital corridors filled with people on crutches, in wheelchairs, with plaster casts, doctors with pagers and stethoscopes, no one notices the trophy of my momentous initiation.

Back home. I am now three hours on the pump. I feel a bit bruised. The biggest inconvenience so far is due to the fact that I forget I am wearing the pump: Stepping out of the car, something heavy pulls my belly: the pump is dangling somewhere at my knees, the canula tugging at my skin. This happened three times in 1 hour. Another annoyance is the pump in my trouser pocket: my pocket feels full and I keep putting my hand in it to 'take out my heavy keys', only to meet the pump. I also have a constant heavy feeling in my belly area, but it is not clear whether this is inside: like I have eaten too much, or outside: like a plaster. My wearing a pump is only a detail: I don't have to adjust the insulin dose or give a bolus. I don't have to test blood sugars before taking a bolus. Most importantly I do not depend on the pump, what it does, what I do with it, how I use it, whether I know how it works, how to solve things about it. So I have no stress, no worry, no fear, no need. I am a free trier of this pump.

Tuesday

The night was OK. Though I kept feeling something in my belly and was annoyed that any time I got up I would have to remember to carry the pump as my pyjamas do not have pockets. Going to the toilet and getting (un)dressed is the biggest hassle, mainly because the tube is the minimum length of 30 cm, I now remember all teenagers I know use longer ones, from 60 cm to 1m10 cm, I guess for this reason, so you can leave the pump in your trousers when going to the loo, or you can deposit it somewhere, instead of having to hold it close. I think I would never want to use the pump, were I a diabetic. It is already annoying me that it is always there, with a tube connected to me, mainly because it doesn't do much. Were I diabetic, I think I'd never want to wear this device always on me, for doing something ***I can perfectly do myself*** *in 2-3 injections a day, and that's it. If the pump had a closed loop system (built in blood sugar sensor and continuously measuring, injecting accordingly), this is something I would not be able to do, so yes, I would benefit from that machinery and might consider wearing it.*

Weighting its benefits against the hassle of being attached to it. Now the only thing this pump does is put insulin in me. I can do this perfectly myself. And when I do it myself, I have my own free body and don't feel incapacitated by this umbilical cord with a weight. Already I want to be 'rid' of it, take out this tube, peel off the plaster and be whole again. Instead it is there: I feel it.

Wednesday

Annoyed with the pump today, I couldn't get it to do what I wanted it to do. I wanted to lock it, but didn't know how and the booklet doesn't say. I push the S button and three other buttons at the same time, the screen flashes with different numbers, the pump beeps but I don't know what's happening. This morning I was shouting at the pump, when I pushed the S button once too often and I had to reprogram the whole 24-hour basal rates again.

Last night in bed I had an ache in my belly and didn't know if it was from the canula, the pump, or something unrelated to it. I was tempted to take it off. Am I giving myself an infection, is this salty water blowing me up? Were I on a pump for real, I guess I'd often be worried. Also worried about whether the pump is working and giving me insulin. Not being in control.

Thursday

The Pump is no more. I took the batteries out. A free belly again.

My main issues with the pump are about being out of control, where is my agency, where does the pump's begin? Mainly, I am continuously conscious this machine is attached to me. I am even more puzzled now: how can the young people forget?

Trying out a pump has indeed enabled me to find out more. However, it has done so by giving me new questions to ask, rather than by embodied knowledge. Of course not. My wearing the pump was merely a tenth of what it really is. No strings attached for me, just a tube I could detach whenever I became tired of the experiment. I am not a young person (33) nor do I have diabetes (or any other major illness). In order to understand the experience of young people on a pump, to understand what diabetes and consequently the pump mean to them, I have to begin from their embodied experience.

2. Young Peoples' Embodiment

This embodiment can be problematic, as young people are twice confronted with their body: by puberty and diabetes. Puberty changes the way their body looks and works. In diabetes one organ, the pancreas, goes its own way —their body, as they know it, falls apart. Their diabetic body not only makes them *feel* hyper or lethargic, it also *demands action* from them: they have to do what so far happened automatically: to administer insulin. Moments when our body confronts us are not usual. Usually, when all goes well, we can take our body for granted. Our body recedes in the background. Here I borrow Drew Leder's concept of *the tacit body* (Leder 1990). He posits that our body necessarily operates in a tacit fashion. When all goes well, the body disappears: "As I gaze upon the world, I cannot see my own eyes" (Leder 1990: 113).[6] In moments of illness though, the body forcefully appears (in Leder's terms, it 'dys-appears': appears in a negative, interrupting way) and cannot be ignored. It demands attention. It demands interpretation, control and intervention of a conscious I. At those moments we wrestle with our embodiment. This can happen in several ways: because of the way our body acts or does not act, and because our body does not allow us to act in certain ways.

Concretely this living with (a body that has) diabetes translates into having to follow management routines: no control over your own activities and time. It also means no control over your body: it can play up and incapacitate you at the most inconvenient times. Diabetes interferes with the young people's lives. And here comes the insulin pump. It gives back to young people what diabetes took away: takes their minds off diabetes and puts them in control again. In control not necessarily of diabetes, but of their lives. With a pump, adolescents can be adolescents again.

The young people in Millness *enact* the pump in such a way so it stops diabetes interfering with their lives. As diabetes interferes in people's lives in different ways, how to stop this interference also differs. Three scenarios show different enactment by different actors, bodies, diabeteses, pumps and contexts in play. The stories of Callum, John and Sara.

---

[6] Though acknowledging bodily appearance at happy moments, like physical exercise, pleasure and taste, Leder chooses to focus on the 'dysfunctional' times. He models his 'dys-appearance' on Heidegger's idea of the 'explicitness' of a tool when it is unusable.

2.1 Callum

As mentioned before, the insulin pump has changed what diabetes means to Callum. Both what diabetes implied in type of medical routines and the restrictions it put on everyday life. Food and being relaxed matter significantly to Callum. "Now with the pump" he says, he can eat and do what he wants. This new treatment has changed not only his diabetes management, but his life. When asked whether the pump means more work he states that actually with the pump it is a lot easier. "You don't have to do nearly as much once you got the canula in, you don't need to do anything. (...) I really don't understand why some people say the pump is much work, the pump does it all for you."

Yet, his casualness may be misleading. While he says he does not need to do anything with the pump, he does a lot. The difference is that what he does, he doesn't see as a chore, or even as doing something, because he does it automatically, it has become second nature to him. What he does not find worth telling, but does several times every day is: count the carbohydrates in what he eats, guess an appropriate insulin dose to cover this carbohydrate intake, administer the insulin to his body. He does this every time he has a meal or even a snack, which must be often, knowing how much he likes food and likes to eat when he is bored, which is all the time. Let's say this is around eight times a day or more. Compare this with the three injections he took each day. The dose was fixed by the health carer, the time was fixed, he only needed to twist the end of his insulin pen to get the correct dose, put the pen in his body, let the insulin get through, and that's it. This would take three short moments of his day, at fixed times. Merely fulfilling the procedure, no thinking, no calculating. With the pump, every time he eats something, he has to think to count the carbohydrates involved, has to think how many units of insulin are needed to cover this and has to 'bleep' to give the correct dose. Remembering that he has to do this with everything he eats, counting and converting, all happens quickly in his head, and he doesn't even think about it, the 'bleeping' he does by pushing the buttons on the pump in his pocket, he doesn't take it out, he just counts the bleeps. The pump is an extremely low-impact means of delivering insulin.

The pump puts Callum in charge. He decides what and when (insulin to give, to eat, to do other things). He doesn't have to stick to routines anymore. He does not have to remember to inject, to test blood sugars, to eat something. He does not have to remember, but he performs the same routines, yet he does them automatically, reacting

to one of his actions and cravings (eating, feeling not well). For Callum then, these are not routines. What he minds about routines is the fixedness in time and the additional schedule in lifestyle which traditional fixed injections imply. The pump made things easier, he does not have to remember and think anymore to take his insulin pens with him. Callum does not like to have to remember. He is good at forgetting. Callum also does not like to have to take things. He forgets and loses them. He does not want to have to take a bag. He carries everything in his trouser pockets, which are heavy with keys, personal stereo, mobile and now also the pump. Callum's quality of life has improved greatly. His experience with the pump is a success story. Diabetes does not keep him from doing anything.

And his health? From a health perspective, things look different. Before the pump Callum was a strict and conscientious manager of his diabetes. He would test his blood sugars five times a day, note the results in his diary, take injections on time and stick to fixed meal times. He had strict blood sugar control. With the pump all this changed. Callum noticed the pump did a lot for him, and he decided to use the pump to his advantage. He started to eat all day, he blew up like a balloon, he quit doing blood tests, kept no diary. His blood sugars rose, his control was less tight. Had he continued to manage his diabetes with the pump, as conscientiously as he did before the pump, his blood sugars would be almost non-diabetes like, and he would have a good chance to avoid complications later in life. But he lives for today. Today the pump allows him to eat ten donuts if he wants to. He feels in charge of his life, does what he wants and is happy.

2.2 John

Like Callum, John was a strict manager before the pump: four blood tests a day, keeping a diary, excellent control. Like Callum, once on the pump, John discovered the freedom of life before diabetes, and quit management: no more testing, no diet. Unlike Callum, this did not work for John, for several reasons. One was his mum, another was his body, another was the pump, in fact, they were all linked together. John is 15, has had diabetes since he was 6. He lives with his mum, a biomedical researcher, and her partner. Mum is very involved in John's diabetes. John was a model patient: good tester, strict control.

When he started to use a pump, things changed. John gave up his diabetes management routines. He savoured the 'freedom' offered by the pump. He describes his pump thus: "It's part of me. It helped me a lot. It made me feel more free about diabetes. I could do what I wanted when I wanted. On injections I felt stuck. I felt stuck for having to eat a massive breakfast, a full-size lunch and a big dinner." With the pump John could finally eat a little or even nothing according to what he felt like, hungry or not. "The pump makes me forget more about diabetes. Like, I still remembered I had diabetes but it helped."

The freedom John talks about is to have to think less about diabetes. It is also having to do less. He stopped doing blood tests: "I wanted to test less 'cause the whole thing about the pump is freedom, it's a big change." This freedom eventually became a poisoned gift. "My blood-sugars were getting higher. I wasn't testing as much, which I now know was a large mistake. I was feeling iffy, had more peaks... it was my fault 'cause I wasn't testing as much. Then it started to bother me. I got sent home from school often for having problems with the pump, like infusion sets were coming out, insulin would run out." "It was lack of maintenance, it was just there, I neglected it." "Then it was getting too much with infusion sets, I got scars. I had pain where they were, I didn't have enough place to change around. I also left the set in for too long, 4 to 5 days. By that time all had become too much." Dad: "It was the only thing we are talking about here. It was dominating everything." Mum: "John started to look like he had this big weight on his shoulders, a big responsibility. He would sit there on the sofa, head down and just like waiting to get it, the criticisms, and then he just said 'that's it mum' and we phoned the nurse and told her John wanted to back to injections." Since John is back on injections, his blood sugars have gone down. He is testing again.

2.3 Sara

"Before the pump, diabetes was a negative thing, all bad, something I was lumbered with. Now, it is something that must be overcome."

While the pump made strict managers Callum and John want to do less diabetes management, with Sara the opposite happened. Having given up on diabetes management before the pump, through the pump she started to take diabetes seriously.

Sara is 15 and lives with her elder brother and mum and dad. Her passion is music; she plays the piano and cello and sings folk songs. A clever and headstrong girl, she'll often say she does not believe in doing things she's not convinced of, so she'll just not do them, unless she sees the point. She lives her life by her own rules. Consequently life is not always easy. She struggles to live life according to her convictions, at school with her teachers, at home with her parents, in clinic with the health carers, who would often call her 'difficult'. Sara was diagnosed with diabetes when she was 12. Unlike Callum and John, she was not a good manager of her diabetes, she had given up, did not test and even did not take insulin anymore. She says injections did not work for her, she felt bad and consequently got discouraged "I probably made it worse, 'cause I wasn't bothered. I was eating the wrong things, forgetting to take my insulin. Nothing was working so why bother? (...) I had given up, I didn't want anything to do with diabetes."

As things could not get worse, Sara was offered a pump to try. As Sara was not interested at all, her mum had to take control of the pump for the first weeks, Sara refused to do anything with it . Today Sara has forgotten this start. Because the pump made a sea change in her diabetes. She noticed the effect of getting insulin in her body, she started to feel better and consequently after three years of ignoring diabetes she took up diabetes management again. I ask her how the pump was for her. "At first I was reading all food packets religiously, the nutrition information on the back, but I got the hang of it quite quickly. I look at what I'm eating and I guess how much I need to add and I usually get it close. Now my blood-sugars have come down and I feel better." Sara's main aim is to feel better. "When my blood sugars are high, I can't move, my vision is blurred, I couldn't read books, which I do a lot, I couldn't sight read the music, when playing the piano. I just wanted to be able to play with my neighbour's children without being exhausted and see what the teachers wrote on the blackboard." "I concentrate on doing the right thing, before I was bingeing on the wrong food, now I eat more sensibly. I've looked at alternatives, at healthy things, so I eat fruit and sandwiches. I still eat chocolate but less."

How come this change? "I think the change... the insulin made the start, then I felt I was better, and I began to eat more sensibly." She had a reason not to binge

anymore, she felt the difference. From then on, once she noticed how good she could feel, she took up diabetes management: mainly by bolusing and by eating less sugary things and chocolates than before. It meant a huge change in her 'doing' diabetes. The pump is her friend, she puts it on the piano when she is playing. In case the cartridge goes empty at night, she has a full one on her bedside table, so when the pump alarm goes off, she puts in another one and it's fine. "I sleep through everything else, but this wakes me up."

On injections, Sara felt she had no control over her diabetes or life, she had given up, nothing worked, why bother. The pump gave her agency in her diabetes and thus in her life. It made her feel better and finally she could see the effects of her own actions.

"*Diabetes is like brushing my hair. It is something I have to do, even if I don't want to. And sometimes it's a nice thing. I can get good results and that makes me feel good.*"

3. The Pump

We have seen how the young people wrestle with their embodiment and how the pump can make a change. For Callum and Sara this change was positive, for John things did not work out. How come the pump can make a change? There are two aspects I want to discuss here, both are related. I start with the relationship of the youngsters with the pump, to then look at what actually happens so the modality of embodiment changes.

"*All human beings need to have a hand in choosing their lives and to be recognized as having an active part to play in the shaping of their social worlds.*"

(Jackson 2002b: 333)

Michael Jackson's existential thesis informs his suggestions for a phenomenology of the human encounter with technology (Jackson 2002b:333). I draw on his ideas to explore the dynamics of Callum's, John's and Sara's relationship with the pump.[7]

[7] Another inspiration is philosopher Don Ihde (1979). In 1979 he stated that the then growing interest of philosophers in the phenomenon of technology came after a long neglect of the topic because idealistic Western philosophy had seen technology as the mere instrument, 'the slave', of science. True knowledge resided in the mind, theory presided over practice (the familiar mind-body dualism). Technology had only been studied by those philosophers who positively evaluated practices, embodiment and perception, like

Critical of an anthropology of human-machine interaction that reduces human intersubjectivity to merely cognitive schemata (see my comments in Chapter 6 on phenomenological medical anthropology), Jackson stresses the importance of investigating how we actually *experience* and *interact* with technologies. These 'intersubjective dynamics' are lived as ambiguous, and balance around what people *can* control of their own fate with technology, and what they *cannot* control. Thus while 'objectively' we may see a person and machine as different entities, in our experience "...our sense of being either essentially different or symbiotically merged with a machine is a function of how we interact with it —specifically how much we feel we understand it and how much control we feel we have over it" (Ibid.: 337). Concretely, as long as a machine works well and does what we expect it to do, we identify with it, Jackson terms this relation between self and machine 'complementary', but when the machine starts to malfunction and does not do as we ask it to, we feel the need to stress the difference, the fact that it is a machine, Jacksons' 'antagonistic' relation.

John clearly was in an antagonistic relation with his pump: things —his body, his diabetes, his life, even his mum— were out of control. Before the pump, diabetes was work, but it had a fixed place in his life, he was in control. The pump upset the different factors in the working configuration, interfered (by malfunctioning, infecting him) and made diabetes interfere. John's sense of self was challenged.

It is clear how Callum and Sara through the pump were more in control, control over the place of diabetes in life. To use Jackson's term, they enjoyed a complementary relation with their pump. Before the pump, Callum was in control of his diabetes, though sticking to routines and management meant he could not always do as he

---

phenomenologists. Ihde mentions Heidegger as an influential force in turning on its head the idealist assumption that technology had been created by science by positing the primacy of praxis: technology happens in embodied praxis and thus science becomes the tool of technology (Ihde 1979: xxv). In his explorations towards a phenomenology of human-machine relations, Ihde suggests that any use of technology is non-neutral, and thus transforms experience (Ibid.: 53). I find particularly useful the distinction he proposes between the 'embodiment relations' and the 'hermeneutic relations' we have with technology. Embodiment relations are in the domain of the experience of 'self' (the machine as selfextension): the experience we have *through* technology, thus technology as *a means of* expertise (for example feeling the surface of the blackboard through the piece of chalk). Hermeneutic relations are in the domain of the experience of 'other' (the machine as other): the experience we have *of* technology, for example working on a computer that gets stuck (Ibid.: 3-16 and 54-55). In these relations, where machines are 'others' "all of the ambiguity of other relations becomes a possibility" (Ibid.: 13). Jackson notes that anthropologist Tim Ingold (1997), like Ihde, refutes the separation between technology and society "technical relations are embedded in social relations, and can only be understood within this relational matrix" (Ingold 'Eight themes in the anthropology of technology'. *Social Analysis* **41:1**, 106-138, in Jackson 2002b: 334).

wanted. With the pump he took the opportunity to forget about the routines, forget about diabetes and he did as he wanted. This proved the perfect combination, he felt in control of his diabetes and more importantly, in control of his life. Sara had no control over diabetes and thus no control over her life. The pump made her see the effect of her actions, she could make a difference. She now has control over diabetes and over life. Through the pump Callum and Sara achieved a stronger sense of self, of identity, what's more, their sense of self stopped being challenged by their chronic illness at all times. Sara sees diabetes now as something she can manage as opposed to "something she was lumbered with"; when Callum talks about his life with diabetes, he always slips into "but now with the pump...".

However, there is more at play than just 'control of oneself'; we can not overlook the rich gamut of actors/actants at play at any given moment. The pump is enacted, not only by the users but by a combination of actors and contexts. This performance changes continuously, as all actors change. Here I take inspiration from the technology-in-action approach by science and technology scholars who stress 'performativity', (such as sociologist John Law and colleagues), multiple performances leading to multiple realities (Annemarie Mol), 'enactment'. A focus on practices. To quote philosopher Annemarie Mol: "Ontology is not given in the order of things, but ontologies are brought into being in common practices" (Mol 2002: 6). [8] These authors stress the plethora of aspects involved in any action and remind us of opening up our lenses to see what is at play. This approach puts an emphasis on relations and on relations of a different quality than merely of a 'controlling' order. While an analysis of the scenarios in these terms would be overambitious, let me attempt a quick taste to show a different, more dimensional story.

The stories of Callum, John and Sara show how technology is enacted in different ways. And although the goal was similar: better-being, concretely: less interference of diabetes in daily life, the way this was achieved —or not, in John's case— differs. Because the entities involved differ. Callum, John and Sara are different people, with different bodies, different diabetes, different parents, different friends, different ways of life, different histories, different aims.

[8] Law & Hassard (1999) *Actor network theory and after*, and Mol (2002) *The multiple body.*

Callum has always managed his diabetes himself, mum accepts this and says it is Callum's diabetes. Callum has himself, his body, his pump and his friends to deal with. His friends think his pump is cool, that's easy. His body is not allergic to the plasters, does not bruise at the insertion site. The pump works well, does not play up and is happy being ignored by Callum for most of the time. Callum himself is comfortable with technology, both with operating and wearing it, no issues there.

John has always managed his diabetes together with his mum. The pump, John's body and his mum do not combine well. John's body does not agree with the pump, the insertion sites infect and bruise. The pump does not behave well: there is always a technical hitch. Mum and the pump do not agree: Mum feels she has lost control, before the pump she knew exactly what was happening, now she continuously fears the next hitch. The pump has taken John's diabetes out of her hands.

Sara did not manage her diabetes. She did not let her mum tell her what to do. Sara hated her body as it did not do as it should. While headstrong Sara wanted to rely solely on herself, she could not rely on her body. The pump changed this. It connected Sara to her body. The pump functioned well, the body reacted well, Sara could act on her body, manage her diabetes and could be independent from her mum.

4. Diabetes in a Box

"*On injections diabetes was 'Aw it hurts', now on a pump diabetes is thinking how much and remembering.*"

Callum

We have seen how John quit the pump because 'things were out of control' (his body, the pump, his management, his mum). It is easy to show what goes wrong to explain why something did not work out. However, merely locating what went wrong will never give us the full picture of what went right. Like Leder's *tacit body* that recedes in the background when all works well, when things work, they are taken for granted. Instead I want to look at what it takes for the pump to work. More specifically, to work for the young people means to forget, to have diabetes interfere less. My point will be that the pump works by changing the way the young people embody diabetes. To make a bold

statement, in line with the concept of multiple reality created in multiple performances: the pump can make a different diabetes. And it can do this when it is incorporated.

I recall my own experience with the pump. And am puzzled. How can they forget about diabetes? What freedom do they mean, with this machine that is always there, as a visible and tangible reminder? The answer is simple. Exactly because it is always there, you can forget about the pump and diabetes. I explain.

4.1 How Can You Forget?

I check with Sara. What's this freedom with a pump, it's always there? "Exactly, it's always there. It helps you with your diabetes." I ask Callum. "Indeed, so you don't have to think to take insulin and pens with you." I persist: "But I found it annoying to carry that machine 24/7 for doing something I can perfectly do myself." Sara disagrees: "It does not do as little as you think it does"; Callum makes an apt point: "Maybe you should try injections for a month, then you'll see the pump makes a difference".

Embodied experience. Injections versus the pump. Concretely, life on injections: dreading the moment you know you will hurt yourself, then slowly pushing in the needle, inflicting lumps and bruises in the process, feeling like a pincushion, and repeat the whole process in three hours time. Also always remember to take your extra bag with pens and insulin with you, a matter of life and death. Life on the pump: inserting the canula once and you can forget about it for the next three days, anytime you need some insulin you put your hand in your trouser-pocket and push the buttons: an unobtrusive gesture, no pain, no fear, like adjusting the volume on your mini-disc player.

Compared to the permanent physical reminder of painful injections, the pump is merely there, on you, doing things, in a non-invasive way. Carrying the pump continuously on you, in you, seems to be less hassle than having to take pens and insulin in a bag with you. Have they incorporated the pump? Is the pump 'embodied'? Their body carries it for them.

The pump puts diabetes in a confined space, instead of it being all over the place and body. The pump offers 'diabetes in a box': diabetes is now a needle, a tube and plastic box. Diabetes becomes visible, tangible and controllable.

4.2 A Machine?

When I wore the pump, the fact that it was a machine and always 'On', bothered me. This machine made a triangle between my body and me —very dualistic thinking, which, as I argued before, appears to be our (adult) Western modality of embodiment. I did not want to hand over some of my agency to the machine.
The machine's agency: I would not trust it to do what it was supposed to do.
My agency was encroached upon by the machine. A confusing experience. Both issues proved to be very different for the young pump wearers: they had limitless faith in the pump doing its job and the pump helped them, gave them more agency.

I share my worries with Sara.
Griet: "What about I would lie in bed and feel something in my belly and I'd worry, is that just the pump, or is something else wrong, nothing to do with the pump?"
Sara: "No, I just Know if it's the pump."
Griet: "Yes, but what if it's supposedly on, but not working?"
Sara: "But it Tells me if something's wrong."
I can't shake Sara's confidence.

I try my worries on Callum: "What if the pump isn't working?"
He replies similarly to Sara: " It tells you if it isn't working, it beeps."
Griet: "Not if it really isn't working."
Callum: "That's why there's all those error messages."
I persist: "But if it doesn't display error messages 'cause it's not working"
Callum: "That's why there is Error 7: saying the pump will stop working."

Callum thinks my worries are completely imagined. Why would a machine stop working? If the batteries are low: there's an error message, if the cartridge is empty: another error message. I am thinking of complete failure: like a piece of dust in the mechanical bit that just stops all, like a watch stops working, but that is due to the battery and the pump has an error message for that. Is my reasoning out of time? I am jealous of his absolute faith in this piece of machinery in its plastic box, helping him in a matter of life and death.

Even if the pump works as it should, what about having a machine so close to you all the time? However, is the pump still a machine for the pump wearers? Or has it become something different/more?

I ask Kathy how she sees the pump.

Kathy: "I see it as a machine."

Mum: "Not like a toaster."

Kathy laughs: "No, not like a tractor, but a machine that helps me. If I didn't have it I wouldn't be here."

I ask Sara to describe the pump.

Sara: "My mum actually put it really well, she said 'it's like a tamagotchi' and it is. It communicates with me, tells me if I need to do something. This may sound strange but I see it as my friend."

Griet: "How does it communicate?"

Sara: "It will go off."

I ask William how he feels about the pump.

William: "It's strange. One friend says I'm a robot, he's full of poo. I find it annoying, I don't like the idea of being attached to a machine 24 hours a day. It's just a circuit board with some plastic case. It's more a gadget that helps me with my diabetes."

John described his pump as "it's part of me, it helped me a lot." Others describe it as "The pump is me too, it's my soul mate" (Karin, 16)

5. Embodiment — Incorporation?

When the pump works well, it can recede and with it diabetes can recede. When the pump works in a tacit mode, diabetes can be present in a tacit mode. Compare this with injections when diabetes meant a continuous confrontation with the body: both the body and diabetes demanded attention, the intervention of a conscious I. With a pump, young people embody diabetes in a different way. From a physical (since painful) illness,

diabetes, as it is lived, has become a more mental entity: forgetting, remembering, thinking.

Can I suggest that the pump is incorporated?
Drew Leder defines incorporation as 'experiential disappearance'.[9] This brings me to Leder's ideas on the 'incorporation' of skills and technology.

He writes how we acquire skills through an incorporation (=to bring within a body) process: "A skill is finally and fully learned when something that once was extrinsic, grasped only through explicit rules or examples, now comes to *pervade my own corporeality.* My arms know how to swim" (Leder 1990: 31)(my emphasis). Incorporation comes with 'experiential disappearance'. When we learn a skill, like swimming, our body is made explicit (not tacit anymore), as soon as we master the skill, the body recedes again. Explaining how to swim, to break up the process in separate movements, again, is difficult.

Leder sees the same process at work in our relation with tools and technological devices. While I find it easy to imagine skills (being ethereal) becoming part of our body, Leder sees us also incorporating technology and devices in the sense that "[I]n its use of tools and machines the body supplements itself through annexing artificial organs" (Ibid.: 30).[10] Over time new skills and, to a certain extent, technological devices disappear from view, they recede into the background, become tacit and "enveloped in the taken-for-granted body from which I inhabit the world" (Ibid.: 32). Thus bodily processes, skills and devices all reside in Leder's *lived body*, which, by acquiring new skills, and using tools and machines, is never stable but always shifting.

In a way, the pump disappears from the experience: the young people forget they have it. The I still intervenes, but in a less conscious way, in a tacit way, through automatisms. 'Seeing' carbohydrates in the food, automatically pushing the buttons on the pump, through the fabric of your trousers, listening to the correct amount of beeps. Operating the pump happens through embodied knowledge, no conscious thinking is needed. When the pump is incorporated, diabetes is lived in a more mental way.

---

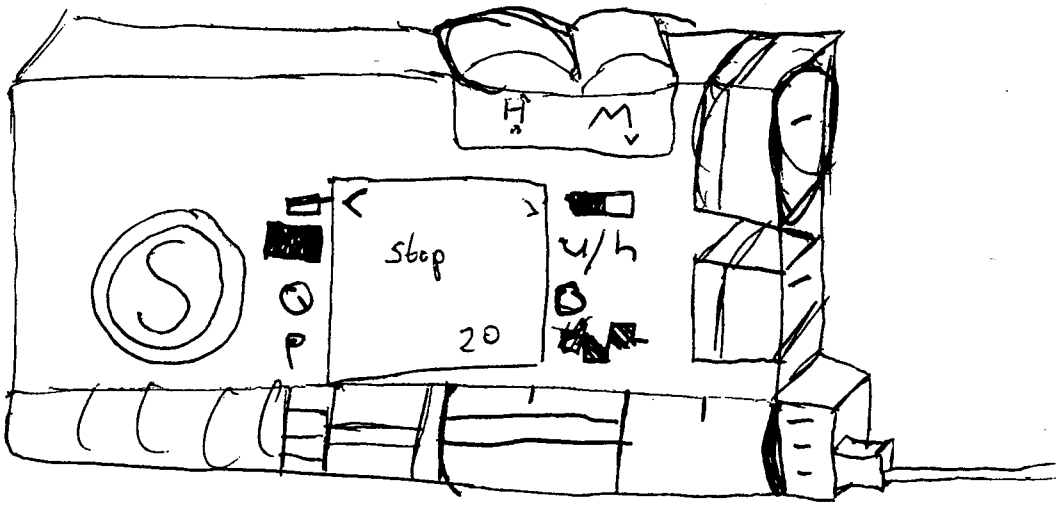
[9] He writes: "Heidegger notes that the "ready-to-hand" tool withdraws insofar as it functions unproblematically. We concern ourselves then with the work and its goals, the towards-which" the tool is used. Only when the tool manifests a certain "un-readiness-to-hand" by virtue of becoming unusable, missing, or standing in the way, must we take explicit account of it. It stands forth as "present-at-hand" because of a dysfunctional break in its employment." (See Heidegger, *Being and Time*, 95-107).

Because they can forget —about diabetes, through the pump, which they can also forget— managing diabetes becomes a matter of remembering. Before the pump, in bruises and pain, they could not forget.

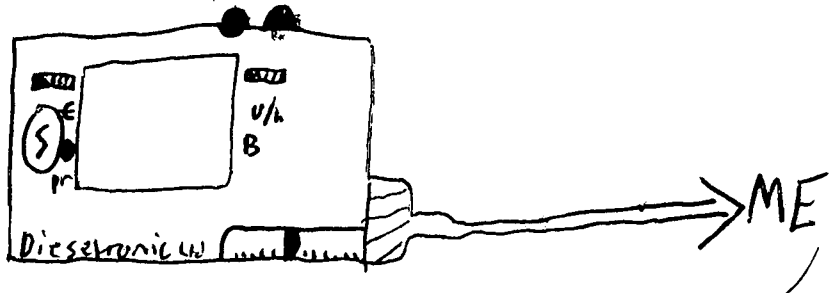
The following drawings (see next page) offer an illustration of this incorporation: being so present in the body, so a part of one's own body as one knows it, that it disappears from experience. For while the youngsters say with the pump they 'forget about diabetes', and they forget about the pump, the pump is actually very present in their head. When asked by me to draw their pump from memory, Callum and William portray the pump in full detail with all buttons, symbols, inner mechanics in place, though they never take their pump out of their trouser-pocket to operate it. In contrast two other young people, who were not very successful in operating their pump (one had quit) drew a pump in two lines, the box and the tube, no 'working' pump, just the material.

[10] He reminds us that the Greeks used one term to point to both bodily organ and tool: organon.

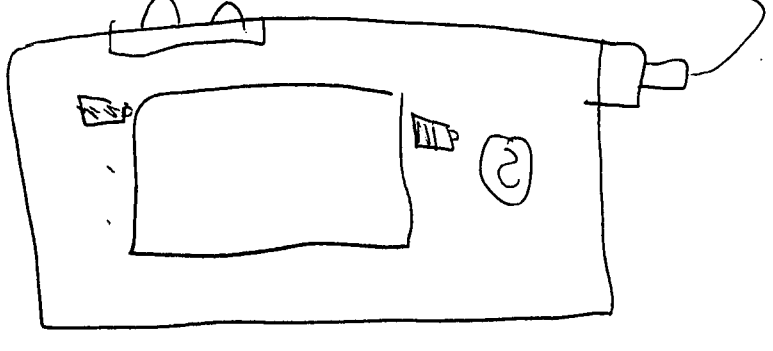
William's drawing (from memory):

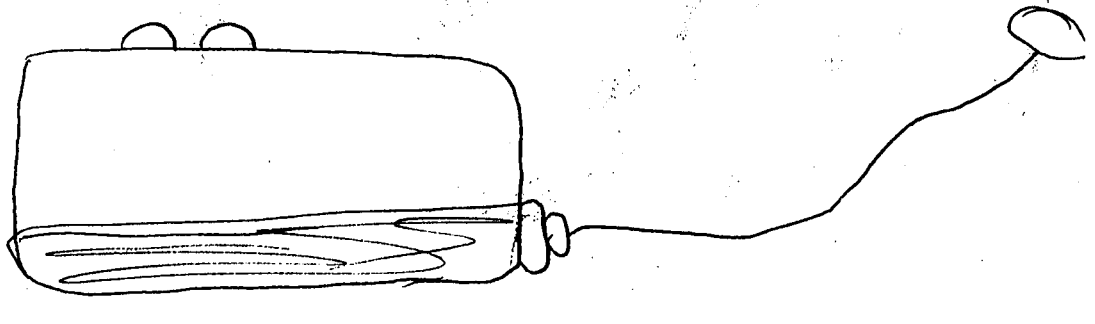


Callum's drawing (from memory):



In comparison, drawings by two young people for whom the pump 'did not work':





To conclude, looking through the perspective of 'agency' is not enough, as a technical device can enable or disable us, whether it does so depends on many factors. Also, 'agency' is no finite amount to be divided: more agency for one actor can augment the agency of another. Perhaps a look from the perspective of technology-in-action has thrown more light on this. Looking through embodiment shows how we can live an illness in a different modality: incorporation of pump and of diabetes: the one through the other. Not just a matter of using a pump to treat diabetes, but of a different modality of embodiment, thus a different way of being in the world. To say with praxiological philosopher Jakob Meløe: "Never say a boat does not shape a way of life".[11]

***

[11] Meløe, n.d., *Remaking a form of life.*

9

Other Centres
Doing Diabetes Differently

When nurse Sheila mentions to Dr. Stuart, leading diabetes paediatrician in Boston, US, how most Millness young pump wearers forget to take their boluses, he laughs discreditingly:
"Forgets? Nobody 'forgets' to take a bolus. Because when somebody is on a pump I have been training them for weeks on how to use it."

Indeed, there are two stories to tell. One is the story just told: that of the young people on pumps, how they enact the pump. The other story is about the context that makes it possible that they relate to their pumps in the way they do: how health carers implement the pump. A change in implementation strategy would change their 'wearing' the pump and their 'doing' diabetes. We have seen how this happens in Millness. Let us now sample other ways of doing.

This observation in other centres is informed by a concrete motive, going back to the medical side of this story: the medical 'reality' of young people, diabetes and pumps. For, contrary to how it may seem from the previous chapter, the Millness pump adventure is nót a total success. The pump mainly 'works' for the young people, because they can forget. While Dr. John and nurse Sheila happily accepted this 'to work' for young people as *the* 'to work', after two years, partly because of growing interest to spread pump therapy to more patients, and partly after visits to pump centres abroad, the Millness team decides to change policy and become more 'directive' about

pumps.[1] Pump use would be conditioned to certain management routines: frequent blood tests (4 a day) and acting upon them with more or less insulin. From now on, the decisive aspect for the pump 'to work' from the health carers' point of view will be whether the pump helps to keep blood sugar levels low.

While this directiveness is good news from a health perspective, it is not so joyful for our pump wearers. The first years this change will not work. The pump wearers have from the start been using their pumps freely and are not used to being directed, and the health carers are not used to being directive. The new approach fails to be communicated successfully: the health carers do not transmit it, the young people do not receive it. A concrete example illustrates.

William has now been on the pump for a year, he feels and looks better, has more energy, he loves his pump and is dedicated to it. His parents are delighted. The only small problem, and he is working on that, is to remember to bolus. I sit with nurse Sally in the consultation room; she goes through William's file before calling him in. She updates herself with his details: "he's been on the pump for a year—"

"...and very happy to be so" I add, stating the obvious, as William's is a famous success story.

Sally sighs: "But his control is dreadful."

I am surprised, as I am about to ask what she means, William comes in with his mum. I guess I will find out more during the consultation.

They discuss William's HbA1c result: 10.2 %.

Sally: "It's still high, the same as last time."

William volunteers: "Which isn't good."

I expect Sally to use this way-in to tell him how he should bring it down, instead she says: "But you feel good?"

William and Mum agree he's been feeling really good.

Sally praises the pump: "What's really good about the pump, they all say they feel well, I think it's to do with the continuous flow of insulin you get instead of two times a day."

[1] Pumps and daily consumables are expensive, so who pays has a big influence on how they are used. In the Millness pilot project the pumps and consumables were donated by a pump company. So no cost to the NHS. At the moment a case is being made to have pumps funded by the NHS. This would come with guidelines to be enforced by doctors: selection criteria for pump candidates, and criteria for staying on pumps, such as HbA1c levels or proof of management routines.

We all agree on that. I expect Sally to make her point now, as she has built up the momentum, when she continues: "So I'm not gonna give you a hard time about your diabetes. Your pump works great for you and your family, you have a healthy lifestyle, a lot of young people could learn from that, take the positive things, give yourself a pat on the back…"

I am stunned. I follow William and mum into the doctors' room, maybe Dr. Veronica will talk straight to him?

Veronica goes over the test results and the bolusing. She then breaches the topic: "I am suggesting, would you be able for a few days to do a lot of tests? You need to find out where you are the rest of the time."

William is quick to reply that that would mean doing tests at school, which he can't, Mum agrees. The issue is left.

Before they leave Veronica tries again: "Diabetes is with you seven days a week (…) you've got this wonderful opportunity, you can experiment, you got all the tools, with your pump, use them. We'll keep things as they are at the moment. Make use of your pump and your testing."

William and Mum leave. Sally joins us in the room.

Veronica looks at me, despairing and worried: "I don't think he'll do it, and it's a shame 'cause he's got the family support and he's clever and he is disciplined…"

Sally joins in: "Yes, he's got the lovely family and it's a shame."

They look at me for my opinion, I say: "I don't think he knows it's that important".

Is this an issue of (mis)communication or does it again come down to not wanting to tell young people what to do? I cannot combine Sally's and Veronica's performance during the consultation, praising William, with their despair afterwards, as if they tried everything to make him see the seriousness of the situation, and he does not realize. They'd have me fooled, I thought he was doing fine on the pump. William still thinks he is doing fine on the pump, Sally told him to give himself a pat on the back. Veronica told him to try and test more during the day, but she will leave things as they are at the moment. William and his mum go home thinking all is fine. When he will be confronted with the concrete requirements of a stricter management, he cannot take it seriously, as for as long as he has had diabetes, nothing was enforced upon him, no threats made.

Similarly when a week later I quiz Sara about the new conditions, she dismisses them. While both William and Sara are happy with their pump and think they are doing well, the health carers talk *about* them saying that if things don't change soon they will have to take them off the pump, as they are not using it properly.
William "I would do it, but I know I'd get depressed, and I won't feel as good about my diabetes", will make an effort to test more and keep his blood sugars quite low.
Sara "it takes away the freedom, I don't like the idea at all", will not manage to do 4 blood tests a day.[2] A few months later she will be taken off the pump, as she was not working hard enough on it and the team, as Dr. Veronica tells me, "could not afford to run any risks with pumps, as the legal situation and funding on NHS was being discussed and so any bad episode or danger could push the whole process back a few years" (as had happened in Britain in the '80s when a patient died on a pump).

How come young people from other centres with strict management guidelines *do* still see the point of wearing the pump, get on with remembering the boluses and testing and achieve controlled blood sugars? Because they are taught and told to do so, and because they have no other option, if you wear a pump, you test and monitor, that's the way it is. Are these young people repressed, less independent, less in control of their lives, less empowered, with poorer quality of life? And also: how is this done?

1. Other Centres

While Dr. Dumoulin's patients practice strict management, I cannot compare Millness pump therapy with Dumoulin's pump therapy, as he categorically dismisses insulin pumps: "There is no point to pumps: the same annoyance (still finger pricks to do the blood tests) and they just add an extra prosthesis. Patients don't want to stand out, with a pump they stand out. Doctors think that even if patients don't have good compliance, with a pump they'll have better compliance, but that is not the case." His patients are familiar and content with their injection syringe therapy, and when prodded, they say they would not want to change a system that works. I could suggest that Dumoulin is so

[2] As seen in the previous chapter the whole point of the pump (to forget) would be taken away by new management rules.

directive that a pump with possible freedom might confuse the strict management routine his patients have made their own.

Thus I look at two other paediatric diabetes centres favouring a more directive approach, where young people practice strict pump management while enjoying the pump and feeling good about their diabetes. These centres are both led by internationally famous diabetes paediatricians, Dr. Stuart in Boston, US and Dr. Thomas in Gothenburg, Sweden. Both publish profusely on pump therapy and are frequent speakers on diabetes conferences.

1.1 Dr. Stuart in Boston

Dr. Stuart runs a private practice in Boston. I visit his centre together with Dr. Veronica and nurse Sheila, to observe his successful practice and to gather ideas.[3] Dr. Stuart has just returned from a diabetes school in Romania where every year he facilitates diabetes workshops and seminars for doctors and nurses. A close colleague at the school is Dumoulin. I see many similarities in their approach to diabetes. Like Dumoulin, Stuart's goal of diabetes care is a low blood sugar level. So *health* is the major goal, accompanied by as good as possible a quality of life. Another similarity with Dumoulin is that Stuart favours a personal and *individual* approach. All his patients see him in his office, they build up a relation with him, as Stuart says "they get to see the same people, we don't have residents that float in and out".

He stresses how every patient is an individual with different needs, which he needs to cater for. In answer to my questions on how he treats this or that he replies with: "we have no rules", "there is no set pattern". Like Dumoulin, Dr. Stuart is also clear and directive to his patients.

70 of Dr. Stuart's 200 young patients are on pumps. He mentions three criteria that all have to be met before he puts a person on a pump: "They have to not be doing well, physically; they have to be a tester (do at least 4 blood tests a day), and they have to know how insulin works." His standard therapy is MDI (Multiple Daily Injections).

[3] As Millness intends to make insulin pump therapy available to a wider group of patients, they are keen to learn from centres and paediatricians with longer experience and (especially Dr. Veronica is interested

Only when his young patients are not well, and Dr. Stuart cannot control the hypos, especially at night, they go on a pump. The pump is thus a choice of therapy only if the normal therapy (MDI) is not successful. Money is the main reason for this. The pump costs $5000, so he finds it too expensive to use as routine treatment.[4] Another reason, why the user needs to do blood tests and be a knowledgeable patient, is that the pump is more work; a patient has to learn how to use it. Patients who are put on a pump are taught extensively both about pump use and carbocounting. They have education sessions with the nurse, the dietician and with Stuart himself over the course of weeks. The first days, they use the pump with a saline solution, while they still inject their insulin with their pens, so they get used to wearing the pump, without immediately taking risks.

The conditions Stuart puts on his patients to use the pump are: to test several times a day, to completely know the pump and the mechanism of insulin, so they can react with insulin and reach the best possible control of their blood sugars: a low HbA1c. They need to take control of their pumps and use it with all it can do for them. Is there any reason he would take people off their pump? "Only when they do something dangerous, like turn it off." What about when they don't take their boluses or omit to test? "I would have a conversation with them about what they were trying to accomplish and whether that was a reasonable way to use this expensive equipment." Would there be a reason to take patients off the pump, e.g. if they are not using the pump as they are supposed to do? "There is no set pattern: I'd have a conversation with the patient, and bring the parents in."

'Conversation', 'parents', 'what they were trying to accomplish': this sounds like Dumoulin. Approach young people as responsible individuals, talk straight to them and go from there. I am reminded of Dumoulin's "c'est du théatre' every consultation is different as every patient and his/her mood are different, the doctor has to read the situation and adjust.

I follow a day of consultations with Stuart. His diabetes centre is situated on the ground floor of an office building. His cosy office feels like a living room: a wooden desk

---

in) good diabetes results (low HbA1c's), as evidenced in the Hvidøre Study (Mortensen et al 1997 and Danne et al 2001).

[4] In the US pumps are paid for by the insurance company of the patient. The doctor needs to send a letter to the insurance company stating that the patient needs the pump. Hence the doctor can enforce (objective or personal) rules and guidelines with pump use.

cluttered with papers and funny pencils, a wall full with figurines and toy animals, a leather swivel desk chair often conquered by the kids so he resolves to sit on top of them. A large worn-out sofa that accommodates parents, patients and any brothers or sisters. Stuart is a quietly spoken, relaxed man, a beard, and glinting eyes. The young children are comfortable with him, climb over him, challenge him over his chair or stickers, he pulls their attention back when necessary and engages them in analysing their test results. The parents appreciate Stuart because he informs them extensively. The teenagers talk and listen to him, Stuart is straight with them and tells them the facts, while at the same time they know he is there to support and advise. They are in this together, Dr. Stuart is an expert and he'll help. It all seems a bit unreal, after having seen diabetes in other places. It is beautiful to watch how Stuart relates to babies' parents, young children, teenagers, quiet shy types, loud and confident ones, struggling ones, all with integrity but adjusted to their personality, moods, and diabetes requirements. Still he can be strict and directive. The nurse of the centre, a sweet mature lady comes in and tells us how happy she is to work with Stuart. What is the big difference with the doctors she worked before? She smiles: "The toughness, he's good at toughness."

Our presence crowds the consultation room: three observers, Stuart, one young patient, plus up to two parents and two siblings. A consultation lasts 30 minutes up to an hour. The young person comes in and tells Stuart how he is doing and whether he has specific problems. For example, sometimes they are 'low' in the morning, how can they fix that? Stuart downloads their blood test meters in the computer and prints out a sheet with last month's readings in a clear colourful graph. He tells them: "this is *your* sheet, not mine." The graph and numbers provide the visual basis to discuss the young person's management. Stuart points out a number on the graph, a too low or too high reading, and asks the patient how he is going to change that. The patient thinks out loud and together they discuss the mechanisms of food, exercise and insulin and come up with a plan of action. Every consultation is a mini tutorial on the workings of insulin and fine tuned diabetes management. At every visit young people are trained in 'thinking' insulin and 'doing' diabetes. Again, I am reminded of Dumoulin. The difference in style with Millness consultations is impressive. Dr. Stuart is engaging, direct and strict, but always caring.

Simon, 16, not very tight control, comes for his three monthly visit. They print out his meter readings and go over the results.

Stuart: "How is your HbA1c now? I am asking because I think it is too high."

Simon shrugs. Stuart says he is not testing enough, he should test more and then he can adjust his insulin dose and get his HbA1c down. Simon says he does not like to test in school when 20 people are watching

Stuart: "You care about testing. Why do you care? Why do you care? Because it might make you a better athlete. You know why professional athletes test 7 times a day? Because they don't want to guess. So just do it. You know your blood sugar level and can give the right dose."

Simon: "I guess it makes sense. I got a question, I am getting my driving license and—"

Stuart cuts him off: "You can't"

Simon does not understand: "Why?"

Stuart: "Because your HbA1c is too high. You can't get medical clearance."

Simon is shocked, he had no idea, they discuss further. Very eager to get his licence, Simon asks whether he can come back in two weeks, so he can work faster towards getting his HbA1c down, with the help of Dr. Stuart. Now Stuart is tough.

Stuart: "It doesn't change that fast."

Simon: "It doesn't?"

Stuart: "Simon, it depends whether you want an A or a C for your diabetes. Maybe you're a C guy, fine. Just be wise. Don't forget it. Nobody's telling you to be perfect, you just have to be reasonable. What you need to do is use your blood sugar information. Testing is the clue and acting on it. Testing is no use if you don't act on it."[5]

Martin, 10, comes in on his own, mum is in the waiting room and will join later.

We just had a conversation about how hard it is to get children to test in Millness. Stuart has replied it depends on the philosophy of the staff. Now he wants to make his point.

Stuart: "Martin, who's keeping charge of your book?"

Martin proudly: "I do."

Stuart: "Is it hard to do?"

Martin: "No."

Stuart: "So how much do you give at 8 in the morning?"

Martin: "Depends on the algorithm…."

Martin tells Stuart how he goes about deciding his dose. Stuart downloads Martin's meter results on the laptop. Martin goes over to the desk, crawls up to join Stuart in the chair. Both look at the screen.

Stuart: "Let's look at your profile at the start of the day. What is the highest part of your day?"

Martin: "The morning."

Stuart: "You know what would happen if we would quit your morning snack?"

Martin: "It'd be lower."

Stuart: "And something else too, you know?"

Martin thinks, Stuart explains. They go over the results together. Mum joins us in the room. Further questions and issues are discussed. Before they leave, Stuart calls Martin: "Martin, you know what you have to do right?"

Martin: "Yes."

Stuart: "What?"

Martin: "Stop the morning snack."

These young people are being taught about their diabetes. Are they being told what to do? Yes, or rather, they are told *how* to do, so they *can* do. If they don't, they are told to shape up. They also know *why* they do: to stay healthy and to avoid the complications of diabetes. Are they being patronized? Is Stuart nagging? As with Dumoulin, these terms never come up. I would say these people are enabled: they are given the knowledge, the tools and the support to be able to take care of their diabetes —which is a medical and physical reality here, *not* a social construction.

At Stuart's centre it felt like things finally fell in place. My six months of worries and confusion over Millness practices were literally acted out in the conversation between Sheila, Veronica, and Dr. Stuart. I insert the most relevant episodes.

Mum and active 5-year-old Elizabeth have just left the consultation room.

Stuart: "Elizabeth, she's impossible to feed, her temperament…"

---

[5] The same credo as Dumoulin.

Sheila: "In the UK, we'd probably blame that for her poor control, whereas here, in spite of that, she still has an HbA1c of 6."

Stuart: "Because she tests, her mum tests."

Veronica: "With us, it's very difficult to get them to do the testing."

Stuart: "It's the philosophy of the staff, that's the only difference."

[*I want to embrace Stuart: what I had been telling (carefully suggesting, rather) for nine months, he just states as a fact.*]

Sheila: "In pregnancy, I would do the same as you, I sit on them to make them get an HbA1c of 6, 7..."

[*Sheila is directive in pregnancy because the patients are motivated to have a low HbA1c and it is a limited amount of time. While she seems to take it as impossible to practice this intense approach all the time.*]

Stuart: "I can make you guys a green clinic. I can get you out of the red. You just need to change philosophy."

[*Stuart is a colleague and friend of Dr. John, he knows the Hvidøre study where the Millness centre has the highest HbA1c results; that is what he means with 'red'. With 'a green clinic' he means a clinic that has low HbA1c results, below the dangerous 9% value.*]

Sheila: "In Yale (another pump centre with good results), they were treating blood sugars very aggressively."

Stuart: "Us too."

Sheila: "I feel uncomfortable about putting teenagers on drugs, they have to take them for the rest of their lives."

Stuart: "Not if I'm treating something lethal like kidney disease."

Sheila: "Then you get into adherence and compliance."

Stuart: "Yes, but I have to convince you why I am doing this, why I am putting you on those drugs. I think I'm aggressive when I start seeing their control gets bad or they're not testing."

Sheila: "But the faff and they just won't do the tests..."

Stuart: "Forget the hassle for a while: what control is important? Like, we don't use any pens, 'cause you can't control anything."

[*Millness uses pens instead of 'medical' and 'hurtful' syringes. Stuart, like Dumoulin, uses syringes. These allow the patient to make up a new mixture of long acting and fast*

acting insulin at every injection time. Pens contain fixed mixtures, making it impossible to react with changed insulin types a blood test, in order to balance blood sugars.]

Sheila: "Weight gain is one of the criticisms of intensive therapy."

Stuart: "The question is: how much weight gain are you talking about? Is 5 extra kilos worse, or do you want a lower HbA1c? I buy a lower HbA1c any time."

Sheila: "What about the teenage population?"

Stuart: "They're worse, like everywhere else, but some are in good shape. This patient is not in good shape, but I know why that is: not much support of family, no checking on him."

Sheila: "That might be the difference between the UK and the US..."

Stuart: "I don't know, US or UK families are equally bad."

Sheila has been prodding for an explanation for the clear difference in HbA1c results between the two centres. Her suggestions centre on Millness' concern for adolescents' *quality of life*: not wanting to make them gain weight or to hassle them. Time and again, Stuart has put the goal of a low HbA1c —their *health* today and tomorrow— over these 'minor' issues. When Sheila takes the mentality of the adolescents as a determining factor: 'they would not do the tests', Stuart replies that it is up to the staff to *make* them do it. Another factor, the difference in families, is rebutted by Stuart, North American families are as bad as British he claims.

Sheila: "People take their diabetes seriously here, probably in the UK as well, *but we don't allow them to take it more seriously*. Before we were leaving, John was seeing the analogy with cancer treatment. You have to say: this is what you have to do."

Sheila has finally put her finger on the difference: 'we don't allow them to take it seriously'. Though, my hope for any change in policy is quick to disappear when she mentions the reason for the 'relaxed' attitude in Millness:

Sheila: "I think the problem in Britain is, type 1 is such a small percent of diabetes patients and there is no focus on that group. Also, here people can choose where to go, in Millness you're lumped with what you get."

This argument, that Millness has to cater for the whole population (motivated and not) and thus cannot be too strict in diabetes care, has come up repeatedly during fieldwork, whenever other centres and stricter policies were mentioned.

Stuart: "All that is true, but you have another benefit that counteracts that: you live in Millness: you go to one place. In Millness, you know you get to see the whole population with type 1 diabetes, you can focus, you can do something."

He explains that in Boston patients can choose between so many places, that as a doctor you get what you get.

1.2 Dr. Thomas in Gothenburg

A second example of a guiding approach to pump therapy and young people is Dr. Thomas' paediatric diabetes centre in Gothenburg, Sweden. I visit his centre together with Dr. Veronica and Dr. Caroline from Millness, again to see and learn.

The paediatric diabetes centre consists of one consultation room in the city's paediatric hospital. The team consists of Dr. Thomas, diabetologist and paediatrician, and part-time nurse Hilke. All patients come to see them every 2 to 3 months, or more often if needed. Dr. Thomas was one of the first doctors in Europe to widely use pump therapy with his young patients and he is seen as *the* expert in pump therapy with young people. Unlike Dr. Stuart however, Thomas sees pump therapy as standard diabetes treatment for young people, thus not only as a second option. Any benefit, even if not strictly health enhancing, the pump can give is welcome. In Sweden the pump is, so far, paid for by the state health service, the doctor can decide freely the conditions of pump use. This general funding is, however, under review, which means Thomas may need to become more restrictive regarding possible pump candidates.

Thomas' goal in treating adolescents with diabetes is "to hope that they have an HbA1c below 9% when they leave the paediatric clinic". To this end there is a "9% club". When patients' HbA1c is 9% or more, they automatically "join" this club: they have to come to the clinic every week and have to put more effort in management, to get out of the club as fast as possible. Even in this club, Thomas does not force his patients;

instead he gets his results by his quiet and friendly manner, and his emphasis on consensus.

In consultations Dr. Thomas shows admirable psychological skills. Consultations take place in the one room, with the nurse and Thomas, and the family. The room is filled with a desk, a sofa and chairs, a computer and cupboards full of pump consumables, meters and insulin. As in Stuart's and Dumoulin's clinic, the patient's meter is linked to the computer and the test results of the last weeks are downloaded and printed. The colourful graph guides the discussion of peaks and lows of blood sugar levels. While in Stuart's centre, forgetting to take boluses never came up as an issue, in Thomas' centre this was the main problem with adolescents on pumps. In consultations, several ways of helping them to remember were discussed, usually all to be rebutted by the patient as impossible.

For example, Karin, 16, has over the last weeks been focusing on remembering to take her boluses, as forgetting them made her blood sugars go high. None of the several suggestions 'put a note on your door, the bedside table, on the fridge, alarm on mobile, ask a friend to remind you, train yourself that food means insulin dose', were adopted by her. Instead Karin decides to set an alarm on her pump to go off when she hasn't pushed any buttons on it for 9 hours. This alarm goes off at 3 am, it wakes her up, she takes a big bolus of insulin and goes back to sleep. She prefers being woken up in the middle of the night to pushing a button at lunchtime. Why? Doing this 'strange' thing makes her special, even brave: see what she is prepared to do for her diabetes, she wakes up at night to take insulin. It causes surprise and admiration from the nurses when they hear about it. If this is the system that works for Karin, she can follow it.

The most striking aspect of the consultations is the relaxedness. The tone is never harsh, Thomas makes his point in a quiet way. A slow pace. Space for the patient to decide on the format, the length of the consultation. There are silences, not uncomfortable, there is time to think, to gather thoughts. Thomas smiles and listens, answers, and suggests. Space also for the patient's personality: whatever their mood, shyness, or bubbliness, they can be who they are or want to be.

Compare this with the Millness consultation 'scenario': a succession of questions, a joke, a quick comment: "How's boxing?", "How's school?", "What do you want to do later?". All questions fired at high speed, by the doctor. While this may suit

some patients and make the consultation lively, even produce a response from otherwise 'morose' adolescents, at the same time it might push away others who just want to be quiet and themselves.[6] Dr. John and his colleagues aim to make the consultation fun, so patients will want to come back. But how much do the patients get out of this? Dr. John is "a great guy", many call him their friend. Though others need more, as diabetes is not all joy, there's frustration, anger and sadness.

My travel companions, Drs. Veronica and Caroline are the two (only) members of the Millness team who are open to a change towards a more directive approach with a focus on HbA1c. Struck by Thomas' manner, Caroline remarks: "If you look at Thomas in his consultations he does not, like us, ask questions all the time. There we are asking: how's the dog, how's swimming? Yet he does have a good relationship with his patients and families." I ask whether she really wants to know about the dog, maybe the young people feel that she is just doing the routine, as the replies to those questions are often mere grunts.

Veronica observes how their job is actually to get a good HbA1c, not to solve the family situation: "We have to remember that. The nurses now are too involved and concerned about the family's life and we're not going to solve that anyway".[7] Thomas makes a strong point of not getting involved in the young people's personal social psychological and family problems. From the start he also told his nurse Hilke not to go there.

Thomas: "I make clear to the patient: 'our job is to deal with your diabetes, our job is to achieve a low HbA1c.' Of course we listen to what interferes with that, but we do not try to solve it. Because I am not a psychologist, nor is the nurse. So we would be doing a disservice to the patient or the family; they need, and have a right to, professional help, we should not try to meddle in that."

---

[6] If teenagers were not full of energy and jokes in the consultation, in the team meeting afterwards they would be called "depressed" or "a real bundle of joy".

[7] A factor here are home visits: the Millness nurses are close to the families as they visit them at home regularly. The nurses love home visits (instead of seeing the patients only in hospital consultations) and do all they can to hold on to them. However, a debate has started that it would be more labour-, time- and cost-effective to abolish home visits and only see patients in clinic. More patients could be seen more often. The teams of Drs Dumoulin, Stuart and Thomas do not practice home visits: they can see patients more frequently —which improves diabetes management— and they get less involved in family problems: by only seeing patients and families in the consultation room, the focus on diabetes is clear.

I would call the difference between the two consultation styles 'realness', meaning that there is no performance in Thomas's clinic. In contrast to Millness, where I often had the impression patients had to perform, fit in, they were expected to be lively and talkative. How to describe an atmosphere? In Gothenburg, the young people 'made' the consultation, it became their own, they did not have to fit in the play, they wrote it, Thomas let them write it. So there were silences and there was not the 'I ask the questions and you answer' scenario. Instead of one-liners both ways, there was a dialogue, a conversation with the doctor and nurse and an opportunity for parents to talk to teenagers about issues they would not discuss at home.

I mention to Dr. Thomas how he gives space to the teenagers. He seems surprised to hear this: "I try to listen to the patient." Does he ever oblige them to do something?

Thomas: "Usually I don't need to. We talk about it. And then *they want help from outside*. For example, they want to come to clinic every week so they can't forget about their diabetes in the meantime. And if they're in the 9% club, then there are extra things they need to do. While I don't want to make them loose face, at the same time I do not want them to do nothing about it, so we agree on something, we reach a consensus of the plan for the next weeks, what they will try to focus on. So it is a consensus, it is not just me telling them what to do."

For example Louisa, 18, who has had diabetes since she was 6:

> "When I got into puberty, 13, I did not want to accept my disease, didn't take care of myself, did not take insulin. Dr. Thomas said that if I didn't change there were two options, I would either go on a pump or be hospitalized. (...) On the pump I noticed I became happier, I did not know that I was unhappy till my sugar came down. My best friend asked me 'but Louisa, when did you become so funny?' Before I was always angry and in a bad mood, I was angry at the disease. When I started on the pump, I would go to clinic every week and we would check the pump memory at the computer, to see if I took my insulin. And I didn't. I remember, there was on the screen this graph and all was flat with this one bar standing up, lonely, the only bolus I had taken. So my mum framed it in a golden frame and she put it on the table in front of me every time we ate. And that helped me not to forget. [*Later Thomas tells me that this golden frame and putting it on the table had been Louisa's own idea, to remind her to take her*

bolus]. I needed someone on me like a hawk. Someone that can tell me what I need to do. From outside."

***

10

Discussion

Doing a Different Diabetes?

In the previous chapter we have seen two concrete examples (Drs. Stuart and Thomas) of a different approach to pump therapy. If we add Dumoulin (Chapter 3 & 4), we have three cases of diabetes care that differs from the Millness approach. Where originates this difference? Can knowing where the difference lies show other teams, like Millness, a way towards change?

I recall the Hvidøre study comparing HbA1c results between 18 paediatric Centres.[1] The study concluded that a possible explanation for the HbA1c differences between centres should be looked for in "cultural or socio-economic differences in the choice of treatment regimens". I recall Dumoulin saying that the difference did not lie in insulin regimens, but that it was 'anthropology'.

While society forms the background in which the health carers operate, it does not determine it. Doctors Dumoulin, Stuart and Thomas are unique in their countries, individual cases that by no means represent the 'Belgian', 'American' or 'Swedish' style of doing diabetes. Similarly, the Millness team is quite different from other Scottish paediatric diabetes care. What I aim to show is how cultural and social context can help, but should not obstruct a certain orientation in diabetes care, as most depends on the personal choice and initiative of the health carer.[2]

---

[1] (Mortensen et al 1997) and (Danne et al 2001).

[2] This is of course in this concrete context of the four cities Brussels, Boston, Gothenburg and Millness that all have state of the art Western biomedical care, with health care available to all, (state-funded in Brussels, Gothenburg and Millness, in Boston young patients without private health insurance would be covered by a state fund), and pumps freely available to all (though the funding arrangements for insulin pumps differ from country to country (US: insurance company, Sweden: state, UK: not funded yet)).

I tell Callum (the 15-year-old boy happy with his insulin pump who we met before) about Dumoulin. I describe to him this Belgian doctor with excellent results, but very strict on his patients and with hospitalisation as soon as someone has an HbA1c of 9 %, and ask what he think about that? Callum scrunches up his nose in disbelief: "Sadomasochistic people that like to be in hospital." I push on: But what if it would be like that in Millness? "I can't imagine Dr. John being strict though, threatening: 'if your HbA1c is 9 you'll be', he seems mellow, he is too laid back for that." To Callum it's a question of personality. I insist that the patients are healthy, it seems to be a choice between being serious from the start, having less complications, or being nice and lenient now but who knows what will happen later. Callum has an answer to everything: "You could also just kill yourself when the complications start to come. I often wonder why old people with many things wrong want to keep on going." (Callum's mum is an old people's nurse.) We divert. I pull him back to the conversation: "So what do you think about this Belgian doctor?" Callum: "It sounds like it works, so it's a good thing."

Would it work in Millness? "Certainly not in Millness." Why? "Millness people are a bit, well.... They don't want to be told what to do." This sounds familiar to me, I want to know more. Millness people are a bit what? "Well, it's a stereotype but well, a bit schemy." Schemy? "Well, like to get things their way." But in the Millness diabetes centre there are a lot of patients who are not from Millness. Are you from Millness? "I am definitely not from Millness." So what's the stereotype? "A typical Millnessian: living in tenements, alcoholic, four kids of different fathers."

So what if we would put such a strict doctor in Millness, would it work? "The attitude from people in Scotland is not right for it to work." How is the attitude? "People wouldn't like to be told what to do." I insist, what attitude? "People don't have the enthusiasm to work on it. They couldn't stick with the strict." These are three different things, being told what to do, have enthusiasm, stick with the strict: what is the real thing, underlying? Callum sighs this is hard. I agree, but I say I am wondering about this myself. He's been abroad, does he think there's a difference? "Oh yes, people are more relaxed in other countries, it's so different over here, in Scotland they are so uptight." Uptight but not sticking with the strict, how does that combine? " In Scotland they are uptight

because they have so many things to do, looking after their own body isn't one of them. Life seems to be going quickly, in other countries it is walking pace. People in Scotland just don't care about their health, they are uptight about anything else. Scotland has the highest heart disease rate." Why is that? Why do people eat so much fat and unhealthy food? "I don't know, I know I don't like healthy food, it doesn't taste nice. We like horrible food because it tastes good." Do you eat differently when abroad? "Yes, I eat more healthy stuff, there is much around."

1. Socio-cultural Context: Ideas on Health and Responsibility

The father of Erik (15), one of Dr. Thomas's pump patients, has lived and worked as an orthodontist in Scotland for a few years and now lives in Sweden again. He is clear on how in both countries the health carer-patient relation is viewed differently:

> "In Scotland people do what the doctor says, in Sweden you need to convince them, you need to reach this consensus all the time. If in Scotland I tell my patients you need to eat with your braces on, they'll do it, if I tell them in Sweden, they say no."[3]

When I tell him how Dr. Thomas just told me that in Sweden patients do as they are told, while the Millness team always stresses how people do not do what they tell them, he explains: "Well it's very simple. In Scotland it's due to *ignorance*, people don't

> know anything about their illness, they don't know, they don't care, the doctor will tell them and they have to take care of it. Patients are responsible."

[*As I did not notice patients feeling responsible in Millness, I enquire. He explains he means how in Scotland it is the patient's responsibility to be healthy, according to the system, in contrast to Sweden where the doctor will phone, chase and summon you or the social services will. Someone takes care of you even if you as an individual don't, it is the doctor's, the system's responsibility to make sure you are OK.*]

[3] He probably is in private care in Scotland so his patients pay a lot of money to see him, so are motivated and will follow his advice, he is a private doctor, he is an expert, worth paying for.

He continues: "In Sweden it is *knowledge*: the people know and read and go on the internet, want to know about their illness, have opinions about it and so they need to reach a consensus with the doctor because they have their own ideas. In Sweden as a doctor I need to explain things, give alternatives. Medicine is a moral thing, of the collective, we chase people. In Scotland my patients say: 'you are my doctor, you tell me what to do'. In Scotland it's more individual, it's supposed to be the individual's responsibility. And they are ignorant."[4]

As ideas on individual responsibility and state interference in health, and more narrowly the patient-health carer relation, can be seen as supporting or obstructing some care approaches, I point at some differences between the centres discussed.[5]

Previously I discussed how Dumoulin in Brussels could benefit from the strong family culture, a climate not allergic to hierarchy and authority in certain guidance relationships (doctors, teachers, priests) and high on individual responsibility for health by doing as the expert doctor advises you. His directive approach did not clash with broader society culture. He had parents who backed him up, patients who did as he said and all families took health and taking care of one's health, in the case of diabetes, as priority.

What about Swedish attitudes towards health, state interference, individuality, authority? Dr. Thomas never forces patients or imposes things on them; instead he gets his results by his quiet and friendly manner. His clinic does not have any DNAs (did not attend). In the case of a patient not coming, Thomas would chase him, keep calling so they came. But what if they still don't come? Then Thomas would call in the social services who would either visit the family, or make them come. If all else fails, which does not often occur, social services are an effective way of coercion.

I ask about these social services, as Thomas mentions them in a positive way. In Scotland listening to the health care team, I got the impression that calling in social services is like opening a can of worms, they are seen as 'interfering', as 'criticising' a family for not doing well. Listening to Thomas it seems they are seen as 'helping',

[4] I have to admit I think Erik's dad makes some relevant points here.
[5] I refrain from discussing US culture as I was unable to study this. Though I can report here the many cases I saw (during my fieldtrip) and heard of patients and their parents seeing their doctors as 'gods', hanging on their every word and taking what the doctor said seriously and as to be done.

when other things do not work, these services make things better. Is this just Thomas's view or does the public think likewise? Thomas gives the example that in Sweden, if a (non-diabetic) teenager is brought into the emergency ward because of alcohol intoxication, immediately the family and the social services are informed. When the teenager is sent home it is with the message that he/she is having deviant behaviour, deviates from community, but that the social services can help him with this. I think of Millness with its high teenage pregnancy rate, alcohol and drugs culture. It seems cool to 'deviate' or deviation would not be deviating, it would be fitting in. If social services thought they had something to say as soon as someone once ends up in Accident & Emergency with alcohol intoxication, there would be a public outcry: "what do they interfere for?" I ask Thomas whether people mind, to deviate from the community? Thomas confirms: "Oh yes. People want to be part of the community, and be normal, accepted."

In Sweden and Belgium health carers know there is a general value system (society) behind them that has some power and persuasion and an institution (social services) that can be called in to help make sure in the end no one will fall off (the society wagon). In contrast health carers in Millness seem to be on their own in treating teenagers, there is no cushioning by society if things get bad.

I would be tempted to write that this social pressure, a community with shared values which people want to belong to, is absent in Millness. In Scotland there is no such fixed framework with agreed upon and valued boundaries that should not be overstepped. Though that would be me writing from my (Belgian) paradigm and values: the value of the duty of taking responsibility for one's own, I have rights in society, but those imply as many duties. However, there *are* strongly agreed upon values in Scotland, as I noticed during fieldwork and have sketched in the context chapter: the value of individuality and the right of self-determination. It is exactly those values the Millness health carers esteem highly and take as starting point for their adolescent care. Unfortunately these values, or the way they are interpreted, are not best suited to guide the care of young people with diabetes. One thing is context, another is what you do with it.

2. Health Carers Acting

Though society can be obstructing (or at least non-supporting), it is not determining: health carers can make a choice. My point is that the Millness health carers take a certain discourse as reality, and hence confirm reality, instead of at least questioning it or deciding it is not good enough and things have to change. And the taste of resignation was always very present in Millness.[6] With the young people, even if they did rebel, rebellion was always eclipsed by, and probably because of, the more general resignation. While Charlie is a prototype, most of his fellow patients also blamed their 'boring' life on living in Scotland: nothing to do, bad weather, no fun. The health carers —by years of experience?— had resigned to accepting the situation as is, taking young people as they are, and still hoping to make the best of it: they might not be able to improve diabetes management, but they could listen and offer support with 'life'.
My question was where lies the difference that can explain the difference in diabetes results? Though not on the basis of a thorough analysis of all variables, but on the observance of diabetes in action over a year, I suggest that a decisive difference lies with the leading health carer. How he chooses and decides to approach care for young people.

Compared to the other centres, it was striking how in Millness diabetes care of young people was characterized by difficulties.[7] Millness could not do what other centres did, or achieve similar results, because compared to the other (countries, centres) they had so many 'handicaps'. "We have the handicap of..." would come up whenever other options or care approaches (concrete examples or theoretical goals) were discussed or observed. We have seen how Sheila's arguments to explain Millness's different results, reluctant teenagers, less family support, a small patient cohort, having to cater for a whole region, were each rebutted by Dr. Stuart.[8] The biggest handicap was the almost impossible combination of adolescents and diabetes. I

[6] I do not wish to judge, the described situations and context illustrate amply the 'no future' and even 'no present' prospects, pleasures, satisfactions, ambitions.
[7] This was general in Scottish diabetes care: (though their concrete approaches were different) most of my interviews with Scottish diabetes health carers were about struggling, problems and big challenges. This in stark contrast to other countries where people just talked about what they did, without complaints or sarcasm.
[8] I was pleased to hear Sheila mention all those factors, as I thought I was exaggerating by trying to explain Millness's care approach by these same reasons. Feeling guilty I was doing them a disservice, as things could not be that simple.

have described how from the start of this research I had become convinced of the 'challenge' adolescents with diabetes were to the health carers: how to reach them, how to get them to manage? It was thus very refreshing, and telling, when talking to Drs. Stuart, Thomas and Dumoulin that none of them talked about this.[9] When, informed by my Millness months, I quizzed them on the 'challenge' and 'difficulty' problem, they said that adolescents were no more difficult to treat than others, they just needed a specific approach, with frequent contact and support.

My question is: to what extent did the Millness team (re)create and sustain the difficult reality by confirming it and acting accordingly?

Just one example. The most used explanation to my questions why they were not stricter with their patients, imposing management routines, was: "with our kids that would not work". Would it not? I do not suggest the team has no concrete base to say this, (as I am sure the young people do indeed often not do as told), but should this just be accepted and become a reality?

I ask the young people how they would feel about for example the approach of Dr. Dumoulin or Dr. Stuart, a strict doctor telling them what to do. While they all say they would hate it, I push on. I say that maybe then their HbA1c would be lower, they'd physically feel good, and have less risk of complications later. I have mentioned (in Chapter 2) conscientious Ewan, who'd wish his mother was stricter with him "to remind me, to have it coming from somebody else", "I feel from my parents and clinic they're not pushing me enough to help get it down". Ewan agrees he would not like it, but it would help. I ask Lisa, who is adamant she would hate it if "diabetes would be made into a bigger thing". We talk about Dr. John: "he's too easy, he's never angry. I think they are too easy on us, like the teachers, and you just don't do as well. They don't make you work. It's OK for the kiddies, but at my age (16) they should switch. When

[9] While a large part of Dr. Thomas's patients come from a nearby boarding school for drop-out youths, challenging young people, no mention is made of this, and I only found out by chance, when 17-year-old Per was introduced to the pump accompanied by two bouncer type guys, his PE teacher and his house master of the school. When asked why they were there, they thought it was a funny question, said it was important to know how the pump worked, in case anything happened to Per. My colleagues from Millness and I were so surprised to see these heavy types even in the clinic, listening attentively over the course of three days, taking notes, asking questions. Something seemed out of place. The above merely to point out that other Centres could also find 'handicaps' to talk about, but Dr. Thomas never makes a point of his good results 'despite' these difficult adolescents'; just like Dumoulin does not boast his results, despite having half a patient population from Maghreb countries, whose sweet diet can make diabetes management a bigger challenge.

people are nice, you don't pay as much attention." Again I do not suggest it would be easy and young people would immediately do as their doctors said, but there is a chance, they know that deep down that is what they want and need, though of course it won't be a nice as things are now. Though, talking to these young people I feel they want to be pushed, and 'challenged' [this word should work in Millness] and made to work. Which is what Stuart's, Thomas's and Dumoulin's patients are made to do.

3. Discussion: From Empowerment to Enablement

From empowerment (in a situation of conflict) to enablement (in a situation of collaboration). I would like to move away from the concept of empowerment. For several reasons. Because power has the connotations of being finite and transitive (given or taken from one to another). It carries the connotation of two sides, a division between the one and the other. One has more power than the other, one can give power to the other, can empower the other. Underneath lies the idea of conflict: one only needs power when something is, or is in the possibility of, being threatened. As I observed in Millness. Instead I want to make a case for enablement, in a situation of collaboration, as observed in the centres of Drs. Dumoulin, Stuart and Thomas.

The difference between the two is embedded in certain societies and values, but in that context is coloured to a great extent by the health carers' choice of *care*.
I suggest that 'appropriate care' (I point to Nel Noddings' notion of care, as mentioned in chapter 5) can make a 'patient' —with the original meaning of patient: 'a sufferer, to patiently undergo'— into an 'agent' —one who acts.

In Millness, care is characterized by the underlying omnipresent conflict situation. Ironically, though the team does its all to avoid conflict, to be understanding, not judging, nor patronizing; exactly what one wants to avoid, of course colours the whole approach. Conflict which is thoroughly embedded in the wider society: the social discourse is one of conflict: conflict between government and citizens, between adults and adolescents, parents and teenagers, teachers and students, in the fields of employment, benefits, health care, education, on TV, in the news, ads, soaps, in the

papers. Talk about rights, not duties. Talk about blame, fault, not own accountability. A fighting and complaining discourse, which sustains itself and becomes more real than reality. —Has an originally convenient way to obtain benefits, care and money by habituation become the standard way of social interaction between individuals and institutions, and between age groups?.

The Millness health carers adopt this discourse, participate in it and build their care from there. An adolescent is in conflict with his parents, teachers, because they tell them what to do, in conflict with his diabetes because it does not allow them to do as they want. Instead of not also becoming part of the conflict, as the doctor who tells them what to do, they will focus on harmony, listen to adolescents, be on their side, accept and understand.

I think because this overarching situation of the adolescents' 'life-in-conflict' is taken as the starting point, the care approach encompasses the adolescent's *life*. Whereas in the general health care setting 'empowerment is 'to give the patient the power to make decisions and take action in their *treatment'* —thus not to 'undergo' (as specified in the word 'patient') but instead to 'do' treatment; in Millness 'empowerment' is rather taken as 'to give the adolescent the power to make decisions and take action in their *life'*— thus not to undergo, 'suffer', decisions or treatment rules by health carers that would impinge on their lives. Taking quality of life as the ultimate goal coincides with this. The health carers first and foremost deal with life, not with an illness. They aim to see the bigger picture, the social situation: family, school, friends and psychological problems. One can wonder whether this is appropriate.

This different focus and goal is reflected in the different style of health carer patient relation, which can be specifically seen in the consultations. Dr. Thomas said: "we talk about it and then they want help from outside". Arriving at a framework for guidance and help, without it being seen as patronizing and interfering is the crucial difference between the centres.

As described, in Dr. Thomas's consultation there was space for joy, sadness or worry, which would be acknowledged and discussed. Not the Millness 'all is fine', 'you are doing great' formulas which start to sound empty after hearing them said 5 times in a row to different people —to me as observer seeing patients come and go, but also to patients who might prefer real interaction, instead of the almost obligation of staying

positive. Harmony and sweetness to avoid the conflict that can come up at any time. Positiveness, and 'you're doing great', as the other side is lurking underneath and cannot be risked to come up. The image of continuously sitting on the lid of a pressure cooker. What's more, does saying: 'Well done', 'You're doing great', 'You're a star' not exactly put more onus solely on the young person, setting her apart from her family and doctor? On top, the Millness' 'You are great's and 'Give yourself a pat on the back' seem to be focused on motivating the young people, though as the young people and the medical results tell us, they don't obtain a lot of motivation for diabetes management.

While Thomas and Dumoulin do not use this fluent motivation chat, their patients are motivated. Motivated because they are not in this on their own, someone will be tough with them and keep them going. Thomas and Stuart avoid setting the young person apart with her diabetes. I did not hear empty sound bites in their consultations. Instead they are understanding and straight. They say 'don't be too hard on yourself, you'll have to do this and this, come in every week, so you cannot forget about diabetes and we'll help you'. Always the message that diabetes is a shared thing. And not only saying, but also doing it. If the Millness carers, like nurse Sally, keep telling the young people in consultations how 'they are a star' and all is well (while they think it is not!), in the consultations there never is real engagement, of the health carer with the patient, and of the patient with her illness. No concrete goal is set, nor is there a challenge to reach it. Consultations are mainly a keeping in touch, not a concrete discussion of tackling the task at hand. Most Millness young people do not engage with their diabetes, they do not take ownership of their illness. You do not get ownership by telling young people 'this is your diabetes', instead you get it by acting like it: discussing it, teaching, working on it, achieving results.

Hence in Millness, though the team is high on 'empowerment', I would say that there is none, and instead the young person stays a 'patient' 'suffering' (undergoing) her illness. —If anything, the young person is empowered, not to manage her illness, but to not act upon it. The discourse on and the approach to diabetes in Millness is such that diabetes is portrayed by the health carers, and hence lived by the young people, as something that does things to you, makes you different, means you cannot do this or that, 'it interferes with life'. In short, diabetes has agency. Dr. John always asks the young people: "does diabetes keep you from doing something?" Doctors saying they

wish they could wave their magic wand and make it disappear. Diabetes becomes an entity, out there.[10]

In analogy with Foucault I could say diabetes is seen as a species inhabiting an organism, according to Foucault the common view in Western Europe before the early 19th century from when disease became to be seen as a deviant state of the organism. This new view entailed the division between normal and pathological organisms and according to Foucault, saw the origination of the 'power of the norm': normality is something people come to positively desire. In contrast to Foucault's model, the desire for normality is also very present and talked about in Millness. Young people saying they are still normal, health carers assuring them they are normal. Reminding them with the typical UK sound bite "It's not about fitting your life around diabetes but fitting diabetes into your life". While sensible, at the same time this can give the idea that doing too much diabetes management means the risk of putting life in second place. At the same time wanting to be normal and thinking of taking diabetes away is not favourable to accepting diabetes (denial is rife in young people) and having to do something about it. No ownership, just undergoing. Which in its turn confirms diabetes' agency: as the illness does not let itself be ignored, if not treated, the monster (the species inhabiting the organism) rears its ugly head, the sugar and body is out of control, too low: hypos; or too high: diabetic ketoacidosis.

While, for example, Dumoulin stresses: "I do not say 'you can lead a life as normal as anyone else', because life with diabetes is different, it means you have to do things, to take care of it, but I do say 'you can have a life as competitive as anyone else'". Most of his patients find it easier to accept diabetes, and the fact they have to work on it. Diabetes, and its management, is made into a technical thing, a task, a job, a skill. There is more distance, diabetes is not their whole person, thus it does not make you abnormal. The 'normal' issue is not stressed, is not a reason to ignore or to mind diabetes, because you are not normal, you have diabetes. And having diabetes means

[10] Also striking is how in Millness a lot of talk by health carers and young people is about how they feel *about* their diabetes (for example William saying when he would have to do 4 blood tests a day he would not feel as good about his diabetes). Feeling good *about* one's diabetes, being comfortable *with* one's diabetes, seems to be another new concept to me, (like 'taking it away' and 'wishing you did not have it'). Doctors Dumoulin, Stuart and Thomas instead asked their patients 'how do you feel?' not about their diabetes but, how are you, totally, as you are shaped by diabetes, diabetes is not something separate from yourself, you can feel (un)comfortable about like your nose or hat. Could you say you feel (un)comfortable about your cancer? Is there a point in discussing this? There is a point in discussing how you feel and how you are coping, but again, that is the whole person.

you have to do things, you are active in it, you do. Hence here the young person has the agency. No point in being depressed about it, it is just an extra task you have. As Dumoulin's patients say: 'that's life, you just have to live with it.' His patients have ownership over their diabetes, but not because it is 'their' diabetes, but precisely because they are in this with other people who help them: their parents, their doctor. Ownership can be shared, agency can be shared, enablement can be shared. Empowerment cannot easily be shared.

Here I have arrived at my 'appropriate care' idea.

I would say the patients of Drs. Stuart, Thomas and Dumoulin are *enabled*: they are given support, education, and frequent contact to work on their diabetes. The framework is one of collaboration. The young person is not on her own, she is helped (being listened to, understood, and kept in line, depending on the situation) by others. Instead of an underlying current of conflict, where all are opposed and seem to vie with each other for the same thing, and where it seems that empowerment for the one means less for the other. As if sharing action over diabetes management means less agency for the adolescent. Agency of doctor, agency of parent, all rival the young person's agency. What is wrong with sharing? Agency of one might mean even more agency, as more enablement, of the other.

In Dumoulin's family cases, it is apparent how by sharing diabetes care, the young person ends up with more agency in its management. As mothers say 'two know more than one'. One does not go at the cost of the other. It is not nagging, interfering or patronizing, rather I would call it enabling, guiding, in short: appropriate care.

Perhaps I can illustrate with the pump.

We have seen how with the pump —that does things and 'helps', thus has agency— the young people also have more agency and accountability in their management. Is there then more agency all round? The pump does not just take over, it puts the young person in charge: it enables. With the pumps it seems to be a plus and plus case. Like with Dumoulin: parents and doctor sharing diabetes with a young person: not one or the other, but both, doing more, enabling each other. Whereas in my experience the pump to me was a plus-minus case: more agency for the pump meant less agency for me, I was struggling with the pump over a finite amount of agency. Like they seem to do in diabetes management in Millness. Where the patronizing and nagging discourse seems

to centre on the principle of 'more agency in one place, less in the other' as empowerment has the idea less with one, more with other,

To recap.
I suggest that a significant factor in the difference between approaches to care of discussed Centres is the idea of *conflict* and *confrontation* underlying and informing Millness diabetes care. I question the conflict scheme. Not saying there is no conflict, but rather that it is counterproductive. Taking the conflict as defining the ensuing actions merely reinstates the conflict, instead of remedying it. Thus I suggest a more collaborative view, which entails a different care concept, focusing on guidance, help, and advice. People can work on something together, it is helpful to get advice, helpful when someone reminds you about something you forgot.

It is nice to share an illness. Parents helping and advising their teenagers, does not mean less agency of their child, but more. Collaboration and sharing means more instead of less, it doubles the total agency and halves the burden. Sharing does not reduce the adolescent's independence, but leads from interdependence to more, genuine independence and enablement. Adolescents get the chance to grow towards independence. They learn with a hand, which goes faster than finding out all on your own and because in diabetes you cannot afford to find out by your mistakes. They learn by doing, not by merely being told. Dumoulin's, Stuart's and Thomas's patients are helped by others and are none the less in charge of their lives for it. Rather, they are more in charge and control.

Though in Millness, something is amiss with 'together'. A helping adult (parent) is only interfering, as 'together' conflicts with the idea of the independent individual. —"You are 12 now, old enough to take care of your diabetes yourself". A culture so high on self-determination, I would expect to be also high on accountability. Though these two do not go together here. Much talk about rights, not about duties. There is always something else responsible: the system, the state, the teachers. The responsibility for one's health also lies with the state, the NHS, the doctor. —Logical, when the NHS promises to take care of me from the cradle to the grave. Could this help to explain the

popularity of empowerment in health carers' discourse, as an attempt to have their patients take up responsibility for their health?[11]

Is this again related to the conflict scheme: everyone takes care of his own and blames others if things do not work? Whereas in collaboration, where in theory one could always blame someone else, as you are not in it on your own, this seldom happens. As the responsibility does not weigh heavily on one person, it is easier to take on, no need to push it completely aside. With shared responsibility, many feel accountable to make it work. When something seems feasible, when you are challenged, can learn, grow and see the effect your actions and effort, you want to do it. You are enabled, you use your agency. Many Millness young people do not really want to manage their diabetes. It is too heavy a task, no results, nor improvement in sight and no one to share it with. Thus they do not take ownership over their diabetes management, responsibility lies with the doctor. He tells them their dose, if the results are bad, it is his fault, he made a mistake.

Am I now saying exactly the same as the Millness health carers told me "adolescents do not manage their diabetes"? The difference is, while they take it as the *starting point* and go from there, I see it as a *result* of the approach to adolescents (and their predicament: adolescents with diabetes) by society and the health care team. I would ask how do we set out from here to change it? A different approach and care could have different results.

***

[11] For example, Dumoulin never mentioned 'empowerment'. It would seem superfluous, as patients feel accountable for their own health and want to take its management in their own hands, under the guidance of an expert doctor.

Closing Remarks

> ***Diabetes***. *Med. [a. L. diabetes, a.Gr. διαβητης, lit. 'a passer through; a siphon', also, as the name of the disease, f. διαβαινειν to pass through.]*
>
> *Oxford English Dictionary*

In the Introduction I mentioned that I wished to steer clear from any model to impose upon the data encountered in this research, having already come across too many fixed interpretive frames in the diabetes world. Instead my aim in this work is to question —by showing diversity and ambiguity— and to suggest other possible ways of doing. Thus in this dissertation I have tried to 'enact' diabetes as in the definition above, by passing through. Pulling the reader along, I passed through diabetes (in hospital, at home, with friends, in Scotland and beyond) in different guises (as fieldworker, as anthropologist-analyst, as a surprised and concerned individual). Now is the time to pull some strands together.

*

I often think about Charlie, the 16-year old with diabetes we met at the beginning, who says he "cannae be arsed". The thing is, he can be. It only took a few days in a different context (place, people, activities) to make this change. At Pinewood diabetes camp over three days the morose "f'ing shiting" teenager made place for a funny, involved and switched on young man, caring about his own and others' wellbeing. However, the Millness paediatric nurses call him a "lost cause" and Charlie indeed keeps neglecting his insulin, landing himself in hospital every other weekend.

Is it naive to think that Charlie could be living a different diabetes-life? Not, as he claims, if only he did not live in Scotland, where he is surrounded by chocolate bars and with nothing to do and nowhere to go, but rather by receiving a different type of care, embedded in a different framework? No guarantee Charlie would fare any better, but at least he would be given a fair chance. And health carers, adults and society as a

whole could feel that they did not accept reality as it is, but worked towards what it could be.

The challenge young people with diabetes pose to the Millness health carers, became in some way my own: what needs to be in place for Millness young people to take care of their diabetes, of their lives?

To gain some understanding, I have observed how diabetes is treated in Millness, then looked at how it is done in other places and I have probed into how differences in approach to diabetes care could explain differences in diabetes outcome. Let me restate the two major points I make in this dissertation.

1. The Construction of 'Adolescents with Diabetes' in Millness

I have shown the specific situation of adolescents with diabetes in Millness as a composite of several interrelating ingredients forming a dynamic mixture. There are the chronic illness of diabetes and its demanding management; the city of Millness with its working class population and unemployment, poverty, unhealthy diet; the Millness diabetes health carers with their concern and support for a holistic approach; the young people with diabetes (I should list all their names here, as all individuals change the mixture); the loose family culture; the societal stress on the right to independence and self-determination at an early age; the discourse on adolescence; the recent notions on empowerment in health care; the discourse on diabetes. Many more, but these are the main ingredients I presented here, none of them static, but making and changing each other.

I have focused on how these elements shaped the concoction of 'diabetes care for adolescents in Millness': an undemanding, non-hierarchical, supportive, holistic approach, favouring (present) quality of life to (long-term) health.

Apart from sketching this situation, I hope my concern about it shone through. For I feel some young people are suffering as a result of the above ingredients coming together. Even though people (adults: health carers and parents) may be acting out of

the best of motives (treating adolescents as having to live their 'own lives'), the results can be disastrous: high blood sugars, micro-and macrovascular complications (blindness, loss of limbs, heart failure) or even premature death.

I hope I have also shown that a healthier situation could be achieved by looking at how diabetes is done elsewhere. Apart from treating diabetes as a serious illness demanding hands-on management, the other major difference with doctors in Brussels, Gothenburg and Boston lies in their relationship with their patients. Treating their adolescent patients not as part of a blanket category but as individuals; acting friendly but not as friends, for they are *not* in an egalitarian relationship: the health carer has the duty/responsibility to care (about the psychological *and* physical wellbeing) for her young patients, even though this may momentarily conflict with her patients' wishes.[1]

The question then is: Why is diabetes care for adolescents in Millness the way it is? Why is it *constructed* like this?[2] For example, how come Millness Dr. John thinks a consultation is a good laugh, while Brussels Dr. Dumoulin engages and works at being truthful with young people and not just their friend?

My stance in this work has been that in Millness, discourse (with conflict) has become reality. People take it as *is*, they do not stop to check, question or go beyond it. Apart from not being very ambitious, in this case accepting reality as is, and not challenging it to see what it could/ should be is irresponsible and not good enough. What I then hope to have done is to abnormalize the discourse, firstly by showing it being done, then by questioning it, both literally and by contrast, showing other diabetes realities beyond Millness. Thus I have attempted to do for an instance of diabetes care, what anthropology continuously does about itself: to abnormalize its discourse: "constantly (building) up the conditions from which the world can be apprehended anew" (Strathern 1992:19).[3]

Since I cannot gratuitously employ concepts like 'construction' and 'discourse', I clarify my position in relation to one of the pioneers of discourse analysis, Michel

---

[1] I stress that the qualification 'young' is essential to my argument about self-determination, empowerment and above all care, as discussed in Chapters 5 and 10.
[2] 'Constructed' as meaning: human beings interacting with/ in and interpreting social/cultural circumstances (health carers), adopting and maintaining discourses guided by their interests.
[3] See Rapport and Overing 2002: 294.

Foucault.[4] With Rapport and Overing (2000: 117-126), I interpret Foucault as saying human beings have no real access to reality, there are only discourses that create specific realities and power relations, and that become the worlds people inhabit; thus people have no control of their lives but are merely the 'effect' of discourses, hence all worlds are *constructed* by historically specific discourses. Understanding Foucault thus, while I agree that discourses maintain ways of knowing the world and power relations between those who are in the know, I strongly disagree with his ensuing characterization of human beings. Consequently I do not use the concepts of 'discourse' and 'construction' as he does. Instead, I concur with Rapport (1996) who critiques anthropological approaches and ethnographies where individuals, as a consequence of consensus becoming the basis of community life, are deprived of any responsibility and become mere collective constructs. He writes: "[E]ven if the social group has become a machine (...this) should be described as the ongoing construction of the people who serve it" (Ibid.: 229). Just as construction is done by people, so are discourses made and maintained by people who partly use them as instruments towards their own ends.[5] Thus, in contrast to Foucault, I stress 'discourse' to say that this is *not* what people are reduced to, rather they are *agents*, who act.

Throughout this work I meant to show how discourses are made, remade, and above all used, yes manipulated, by interpreting individuals, guided by their own interests and needs. My point was to make the discourse (on adolescents and diabetes) so explicit —in fieldwork, by continuously asking informants 'Is it?', 'Why?' and 'What if?' and in the analysis, by wondering and showing differences from elsewhere— as to break it up, dissolve it, so people could then start again (probably with another discourse, though preferably with many different individual ones: life stories).

Concretely.

The British 'discourse on adolescence' is taken as a reality. A discourse in which *conflict* is the main theme and which colours the ensuing practices and form the base of the health carer – patient relationships.[6] Diabetes care for adolescents is focused on containing the lurking conflict: health carers are chummy, give support, and try to be

[4] With 'discourse' I mean "a body of knowledge content" (Routledge *Encyclopedia of Social and Cultural Anthropology* 2002: 162-163), and "ways of speaking which are commonly practised and specifically situated in a social environment" (Rapport and Overing 2002: 117).
[5] See also Rapport 2002: 124 and 1996: 235.
[6] As discussed in Chapter 10.

friends. In Sweden and Belgium, of course 'tensions' are present in people's ideas about adolescents and the rest of society, but conflict does not become the characteristic feature of adolescents. Furthermore, there are strong unifying and containing forces, such as the family (Belgium) and society (Sweden). Thus diabetes care can afford to mainly deal with diabetes and a genuine (and unequal) relationship can grow between health carer and young patient, they can agree and discord, talk 'honestly', state tough 'facts', as there is no continuous risk of alienating the young person and thus upsetting the fragile balance. Because there is a cushioning circle (family and society) beyond the 'young person, doctor and diabetes triangle.

The British conflict theme travels with the idea of a society made up of independent individuals having to take care of (and fend for) themselves. Especially in adolescence this independence becomes acute. Parents, teachers, media and, yes health carers, tell adolescents, from the age of 12 onwards, that they will not tell them what to do anymore, as they are leaving childhood and will now have to look after themselves; it is their life.

Exactly. While I agree it is their life, I follow a different trail of thought. Their life should be taken good care of, but not only by themselves. For they are not adults yet, and they are not yet in a position to know and to make informed choices. 'Choices' they make now impact the rest of their lives. So they can use all guidance and care they can get. If guidance and care seem to go against ideas of empowerment and self-determination, I would say that the latter terms are ill-defined. To care and to be cared for do not mean a loss of individuality, rather it allows us to be an individual.[7] For this is not dependence (one individual depending on another) but a shared interdependence, which makes us more instead of less.

Perhaps the relationship between young people and their insulin pump could serve as a scale model for a different approach to diabetes care in Millness. Instead of conflict (between machine and person) as the operating theme, with ensuing issues of power struggle over finite control (more power for one means less for the other), successful pump stories centre on collaboration (between machine and person), achieved by inclusion, almost incorporation of the pump. More 'power, control' to one, means automatically more to the other.

[7] See for example Anette Baier's ideas on trust and care (1985: 99).

As witnessed in Brussels and Gothenburg, where parents and health carers shared diabetes and its management with the young people, this did not mean a power struggle or less independence of the adolescents, but rather an interdependence, an inclusion. Hence the idea of seeing things as hanging together in mutual inclusion (Mol). Or to paraphrase Suchman, agency is not something contained within singular entities. It is relatedness, not separation and autonomy, that is the mark of humanity.[8]

In the introduction I stated how this dissertation could be read as a concrete example of how a technological device is embedded and put to use in a specific social and cultural context. My previous point then —which coincides with Part One of the dissertation— is the specific social and cultural context in which the insulin pump is embedded. My second major point —Part Two of this work— is how the pump is put to a certain use.

2. The Insulin Pump in Millness

The new type of insulin therapy was actively introduced to the young people by the Millness paediatric team in a specific culturally, socially and personally informed mode.[9] The young people and their families in turn, took up this new therapy in their personal ways. Thus I have shown that people are not, —as technological determinism would have it and as contested by Marilyn Strathern among many others— "passive recipients of products" (Strathern 1992: ix), but rather "active consumers", using technological devices to their own ends.[10]

Concretely in Millness, both the health carers and their young patients are active consumers of the insulin pump. The health carers, fully in line with their hands-off 'empowering' approach, present the insulin pump as the herald of freedom: the pump allows you to do (eat, sleep, do sports) what you want, when you want. The pump is

[8] Based on Suchman n.d.: 5.
[9] Similarly, the paediatric teams in Gothenburg and Boston introduced the pump in respectively their specific social and cultural contexts and approaches to diabetes care.
[10] In the introduction to their edited volume *Consuming Technologies* (1992) Hirsch and Silverstone mention how the production of technology continues in its consumption, in a mixture of strategy and tactics (Silverstone & Hirsch 1992: 3).

introduced with emphasis on its benefits to quality of life; its significant possible benefits to health are not explicitly stressed, as this is not what makes young people tick. The way the health carers put the pump to use, informs how the young people use it, again according to their specific personal priorities, be this doing what they want, forget about diabetes or instead actively control and manage it.

Above all, what I hope to have shown is how technology, the pump, does not dictate, but *enables*. Eric Hirsch (Silverstone & Hirsch 1992: 3 and Hirsch 1992: 210) mentions how technology is made meaning full in different ways, how it is involved in the definition of our identities. I think this shone through in how the young people relate to their pumps (Chapter 8). The pump enabled some young people to forget that they had diabetes. It enabled some to experience a different illness, one that was less invasive, hurtful, ever-present and debilitating; for some even one that was better manageable. The young people employed the pump to make diabetes recede into the background, so they could get on with teenage life.

However, in the Millness hands-off, quality of life-favouring approach, basic conditions for pump usage, to ensure not only optimal health benefit but even safe use, are not enforced. Technology enables, but can only do so to the full, when people know how to use it and are informed on its possibilities, benefits and uses. Only then are its users fully empowered. In the words of pianist Barenboim (2006): "Ignorance has not yet for me acquired the category of free will decision"[11]

This brings me back to the underlying conflict theme. In Millness diabetes care, quality of life is seen as conflicting with good health. Concretely, performing the management routines that can bring about good diabetes control and limit later complications are seen as impinging on everyday quality of life, consisting mainly in doing as you want. Not having diabetes interfere with your life.

Nevertheless, in order to limit the interference of diabetes in your long life, you need to allow some space to diabetes management in everyday life. Centres like Brussels, Gothenburg and Boston follow this strategy. Again the insulin pump can serve

[11] (The Reith lectures, April 2006, BBC Radio 4). Though he was addressing a different topic, whether classical music education in schools was desirable rather than enforcing and patronizing, I find his reply very appropriate in this context of lack of diabetes and pump education.

as an example of collaboration. In Gothenburg and Boston, patients are educated to use their pump actively, achieving both health and quality of life, without the one seen as impinging on the other. Rather, using an insulin pump benefits both. The young people are truly empowered and expert patients.

To conclude.

I have shown the agency and creativity of people, both with each other and in relation to technology. Like people, bodies and discourses, technological devices are not uniform products, rather we continuously actively fit them into our lives. We make both use and sense of them. But this is never a fixed situation, the configuration of users, technology and circumstances is continuously changing, each informing and shaping the other.

As in Chagall's *Illustration for The Circus* on the cover page: a collaborative performance, a balancing act made up by the acrobats, their tools, the circus tent and the audience. A hanging together, in flux, ever changing.

What Next?

Already during fieldwork there were signs heralding a change in composition and philosophy of the Millness paediatric diabetes team: younger health carers joining the team and bringing their convictions with them. The study trips to the Gothenburg and Boston centres made an impact and inspired a move towards a stricter and more hands-on approach. It would be fascinating to observe, in a follow-up study, how three years since this fieldwork ended, both the team and diabetes care for adolescents have changed.

Another follow-up would be to visit the young people portrayed in this dissertation. How are they three years later and older? Have some changed their ideas on diabetes, do they live diabetes differently, do they have regrets, how would they react now to what they said and thought three years ago? And how have William, Sara, Callum and John fared with their pump? Are they still wearing one, have changes in their daily life and activity affected their relation with the pump?

A third panel of this follow-up study could be the 'political' situation of the pump: has health research led to new health policies on the insulin pump? Are pumps now funded by the NHS and under which conditions (stated in the SIGN and NICE guidelines)?[12]

A theoretical issue that will keep me interested for much longer is the relationship between human beings and machines. How does agency relate to technology, where (if at all) does embodiment come in? Science and Technology scholars and increasingly anthropologists keep coming up with fascinating diverse takes on this topic, which will become an ever more prominent theme in future.[13]

Finally, I will keep searching how to write "authentically": eclectically combining theories, genres and media. Perhaps this is the way to write phenomenologically.

---

[12] For most recent updates consult http://www.sign.ac.uk/guidelines/published/index.html#Diabetes, holding the SIGN 55 *Management of diabetes* document and the 2005 review report.

[13] For example the edited volume by Lock, Young and Cambrosio (2000) *Living and working with the new medical technologies:intersections of inquiry*, investigates how medical technologies are produced and practised through 'intersecting lines of action' (see also E. Sobo's (2005) review article). The contributing STS and anthropologist authors conclude that "despite shared concerns (...) deep epistemological divides remain (between the authors)" (Lock et al 2000: i).

Appendices

Appendix 1

Pinewood Camp

Pinewood Camp is organised once a year and gives 20 young people with diabetes (age 16 -20) from the UK, the opportunity to spend a week together, engaging in outdoor activities, meeting each other. It is also a chance to learn about their diabetes in a practical way, as physical activity influences blood sugar levels and if needed, medical assistance is at hand from six diabetes health carers. Pinewood lies on the private shore of a loch in the Scottish Highlands. All activities (kayaking, canoeing, windsurfing, sailing, mountain biking, hill walking) take place from there. It means that for eight days, no one leaves the site and everything symbiotically merges together: the 30 participants of the camp (both students and health carers), the loch and the surrounding highlands. There is a certain magic about these eight days. The length of time gives people the chance to get to know each other and to know themselves a bit better. For most teenagers 'who never even run for the bus', those days of strenuous activity are challenging and confronting.

A log cabin on the shore of Loch Eden. Bar, drying rooms and washrooms at cellar level, at ground level the kitchen, dining room and bunk-bedrooms with a view of the loch and Ben Pine. A little harbour with two motorboats and a few dinghies, big wooden sheds with canoes, kayaks, surfboards and mountain bikes. Apart from the camp centre, no house or any civilization to be seen, just us (20 young people with diabetes, 6 health carers, 4 sports coaches and 1 anthropologist) the lake and the mountains, for eight days.

In the minibus to the station to pick up the 'students' (as the young people with diabetes are called at the camp), David, the sports facilitator of the camp, tells me how he and the head doctor differed so much and how now after many years the head doctor is coming round to his side. The medical staff is now finally starting to see David's point, they are becoming stricter and are finally setting the students some boundaries.

For example, one year a doctor went into town with the car to buy some cigarettes for a youngster who had run out. David says: firstly plan ahead so you don't run out, and secondly let the youngster go and buy the cigarettes himself on the bike. Another issue is underage drinking. As under 18's can't drink alcohol they also can't sell them alcohol at the bar of the camp, something that did happen though, and 16- and 17-year-olds got drunk and sick. I enquire what about sex? David doesn't mind so much about that but says staff have become stricter over the years. David explains that this camp started 18 years ago, because diabetes care for young people didn't really exist, so the camp was organized for young people to meet other young people and learn something. However, now with all the gimmicks, trendy blood testers, pens etc. treatment is geared towards young people. The main purpose of the camp now is not so much to just do *something* for them, but that they should experience doing things they can't do in daily life. Last month at a meeting to get the camp back on the rails, David suggested that the medical aspect should be more present. He finds the medical team too loose, they mainly want to bond with the young people and so do everything for them, even giving completely the wrong message like buying cigarettes or selling alcohol to under-aged. David was a secondary school teacher for a few years and he placed firm boundaries on his class, the teenagers knew this and respected it, he claims.

The first evening, after dinner, staff and students gather in the cellar meeting room- annex–bar. Relaxed head doctor John welcomes us "you are here to have fun". Coach David gives us some straight talk explaining the system of the camp and some rules (the daily schedule, where to go, what not to do). Nurse Jane then closes the meeting with the yearly 'hypo chat'. That is, it was always called 'hypo chat' however this year she decided to call it the 'How to have a good time' chat, "because that's what you're all here for". "Of course you will participate in the sports activities and there is the chance that you will get a hypo from that so remember to eat enough, not to drink too much alcohol and reduce your insulin dose by 25%." As soon as Jane mentions 'insulin' which she has successfully avoided for ten minutes in this animated chat (funny noises and visual effects, all about fun) and then also mentions 'hypos', the first sigh goes up. The students can't wait to get out of this bore and for the bar to open, buy drinks and get to know each other. A brave boy has the audacity to ask: "Is that why you reduce your insulin when you do sports?" and another big sigh fills the room.

Doctor John finishes the talks, wishing us all a good week. To wrap up all students are asked to say why they are here: all of them are here to either "have a good time", "to mess around" or to "have a laugh" (x 20). One girl says she is here to meet other people with diabetes.

9 p.m. The bar opens. Though most students (aged 16-17) are underage, lots of alcohol will be sold all nights, by teenagers running the bar. The students take their bottles outside, to the benches at the harbour where they spontaneously gather throughout the day, and in the evening to drink, talk or lounge about. When it gets too cold (11 pm) they will move to the dining area or hall inside and then to one of the bedrooms, to end up in bed at various times between 12 and 5 am.

While the young people are drinking and getting to know each other, so are the staff. They sit in the bar, drinking vodka and bottles of wine, planning the week ahead. Over the week they will move on to the 'staff room' where they will drink and chat till early morning hours, fuelled by gin & tonics and whisky. They have a good time and like the students they eagerly anticipated this 'famous' camp. Two junior doctors, 'first-timers 'on the camp, know each other from their training days, four other health professionals (two nurses, the head doctor and the sales representative of the company sponsoring the camp each year) are 'regulars' and each on their fourth camp. One anthropologist, myself, to whom all is new. Neither member of staff, nor 'student' with diabetes, an in-between. Though the staff is never introduced, it is fascinating how the students pick up on who is what. Over the next days some students will get close to some members of staff, playing games or asking for specific diabetes advice, some girls mainly to have a chat.

No introduction also means that no one, apart from the medical staff, knows I am not a medically trained person. Over the days I sometimes feel the need to mention this, when the students ask me about their blood readings and how they should adapt their dose. Similarly every morning when each activity group gets two members of staff assigned to it, in case anything happens. Diabetes related episodes will occur quite frequently during the week, which is half the point of the camp: to have young people experience what happens to their body and their blood sugars when they do some physical exercise, how they need less insulin, because their body takes up some of the sugar automatically. Hypos are a common occurrence.

Thus over the next days, I constantly try to figure out my position. How involved am I allowed to be? Am I expected (by the staff) to sit back and observe? No, doctor John told me to talk to the kids and participate. I do, but I also wonder how much the young people want me to be involved. When I talk to them, how annoyed are they that I am asking them questions? Do they perhaps think I am only chatting to them to find out about things? I don't want to upset any possible balance there might have been without me. I do not want to be here observing and analysing, I want to participate, however, how and as what? I am not a student with diabetes and I can't do anything practical medically, or give them advice. This self-consciousness about my outsider position proves unnecessary. By the end of the week by chance I realize that many of them don't really know what I am, nor do they wonder. Some think I just have diabetes, others think I am a health carer. In contrast the staff are aware that I am an anthropologist and (unwittingly?) make me conscious I am. I am surprised when head doctor John comes to me during the hill walk the first day asking "Do you know why Chris had a hypo last night, and now he is running around helping others and is full of energy? I would think an anthropologist would look into this." When I suggest this might be more of a chemical/ physiological question, John does not seem satisfied with this reply, and rejoins the nurse walking in front of me. During this last year I have heard so many strange expectations from people about anthropology and what anthropologists do. Especially in a medical setting where professionals are so involved with practical issues and results, it is often difficult to try and define why I am there too. *They* are treating patients.

As a bonding exercise and to provide a sense of achievement, the first day of the camp is traditionally dedicated to climbing a hill. This is a bold enterprise since most of the students at the camp are characterized by the health carers as 'the closest they ever get to exercise is to run for the bus.' On top of that, this morning the majority sports a major hangover and suffers from sleep deprivation. As we get on the bus to take us to the bottom of the hill, many protest "Do we have to go? Can't we just want to stay here?" During the walk, frequently students will stop and say they can't go any further. This is after the first 10 minutes flat walk, the Munro looming cheerfully ahead of us. The hill walk leader walks steadily and pauses every half hour so the whole group can catch up. The protests, the nagging, the "I am going back" galore. We are driving a reluctant herd up the hill. Some youngsters walk with their headphones, some smoke.

We must be a colourful sight: thirty people dressed in 'Pinewoodies' (as the camp's waterproof attire, bright orange, red or blue one-size-fits-all jackets and trousers are called) walking up a mountain, in thick mist and sporadic rain. Every so often a student feels weak and shaky and has to sit down, John, Sheila or other carers stop, take out the blood sugar meter, measure the sugar level and administer dextrose. All members of staff continuously carry a bum bag with meters, insulin syringes, Hypostop and Glucagon in it. I am merely given a bottle of Lucozade and some mini Mars bars, in case of hypos. It instantly gives me a justification to be there, feeling part of the diabetes scene. During the walk I will gregariously ask teenagers whether they need some Lucozade. It gets very foggy and wet. Hair and faces dripping, unable to see beyond the person in front of us, we have to make sure to keep up. Under these conditions we reach the top. In clear weather the view is splendid, today we are in the clouds and can only imagine. It gives the situation a mystical feel; we are at the end of the world, exhausted and around us only clouds. We eat our packed lunch before starting the descent. Surprise: no more grunting, complaining or nagging, people are laughing, teasing and chasing each other down the hill. Most of them are so surprised they made it to the top, going down comes easy. We arrive back at the camp wet, sweaty and cold, a race for the showers and ready for a satisfying evening meal. The students are elated, exhausted and chatty. They pulled, and mainly were pulled, through. That evening many are on their mobile phones calling home "We went up a mountain today" "Honestly, we walked all day" "I was talking to my mum and she couldn't believe it." "I am so proud." The hill we climbed is the backdrop scenery of the camp, we see it when we are kayaking or sailing on the loch. Our personal skyline greeting us in the morning, our sunset postcard in the evening. The mountain becomes a reference point for the rest of the week. "I went up there, I still can't believe it." "Wow it looks high, it's amazing, we did that" "I never thought we would do that". The Ben is a visible reminder to the young people of what they can do and what they did, even if they never thought they could. When I ask Nick, a tiny 15-year-old rough hackney boy what he thought of the walk, he says it was 'easy-peasy'. —Really? —

Nick: "Yeah, it wasn't hard."

I tell him I am amazed, as he was even smoking during the walk, he must be so fit.

Nick: "Well, actually, it wasn't easy at all..."

Nick asks whether there'll be an evening program today. I reply there might be a lecture on diabetes. When he replies "boring" I ask him, referring to the other bits of conversation we had when he always said 'boring', why he came to this camp?
Nick: "To get away from London."
Griet: "Why do you want to be away from London? It must be an exciting place, you complain things are boring here..."
Nick: "To be away from my brothers, to be away from.... Just to be away."

Every morning after breakfast and before outdoor activities start, we have a discussion group. Talking time for the students to ask questions, to have a chat about diabetes, or any other topic. I am with (nurse) Sheila in a group of five young people. One morning we will sit under the big tree in the little harbour, only to be chased away by midges, we will then take refuge in the boat shed, or move to other benches under other trees. We meet with this same group every morning, so we can get to know each other and get confident. Our group represents a microcosm of the camp as a whole. Alison, a big girl and loud mouth at evening drinking times, will hardly say a word all week. When once asked to give her opinion, she'll say she rather listens than talks. Bony Tom will spend at least half of all discussions lying flat out on a bench or simply on the ground, sleeping or dozy, recovering from last night's entertainment. Karen, a cheerful Welsh party girl will chatter away and will even dedicate one whole discussion session on teaching everyone the tango moves. The last group members are two very mature boys. Phil, the eldest boy, 21, tall, crew cut, works as a salesman in a bike shop. With his quiet and imposing presence, some younger boys see him like an older brother and will often seek his company. Phil is the one who will always, and in the most impractical situations be it on a boat, on the bike, even on the surfboard, take a bottle of water, some glucose tablets and some chocolate along on the activities. He takes this not for himself but for the others in case they go low. He is very attentive about the other young people and will ask them whether they are OK, whether they need to test their blood and so on. Phil is the only student at the camp who came in his own car, so every evening he gets to drive a full carload into town so they can buy their necessary spirits. Phil will talk very openly about his diabetes, how he deals with it, how it is difficult for him sometimes, how he didn't deal well with it a few years ago but then came to realize he was only fooling himself and how he sorted himself out. When he mentions he doesn't mind when his friends and family want to practice giving him injections, this

provokes a disgusted reaction of the others in the group "oh no, no one is allowed to do that, I do it myself". Stan, a 17-year-old tall and blond boy, well educated, very sporty, from a well-off family, studies engineering. He is also quite sorted with his diabetes. He tells us how strange it was for him last night to see that there is no sugar on the tables, only 'disgusting' Canderel. "Like yesterday evening, there were strawberries, mmm, and ... no sugar? [*He holds up both hands as if he were holding the strawberries, and looks at them in a confused way*] I was like: what do I do with the strawberries if there is no sugar to put on them? At home we just eat normal and my mum doesn't give me any special or different food or such, I just sort it out myself. And in the (diabetes) clinic they keep telling us 'you are normal 'and, I mean we are not functioning 110% normal but we are normal and then we come here and suddenly: no sugar? As if we aren't able to handle that ourselves."

Another day as we are discussing whether having diabetes makes them different, Stan says he just wants to be normal, and he is normal, well he feels normal, he is used to it now, so it is just normal. He doesn't want anyone to treat him differently or special because he sorts out his regimen and his diet himself. Phil: "I am so used to my diabetes, I don't know how it would be to all of a sudden not have it anymore, it is like, it's a part of who I am." He seriously doubts whether he would want a cure "I would be missing something, something which was with me would be gone". The others strongly disagree, they would love there to be a cure. "Yes, I am used to it, but still, if I could be normal and not have it...."

Sylvia, one of the most mature students, is a bright and fit 21-year-old, a lifeguard at her local swimming pool. As we are in the same activity group, we spend hours chatting away in the canoe or dinghy. During this week she takes the opportunity to see the effect of different activities, routine and diet on her body and blood sugars, as she wants to experiment and learn. She often tells me how confused she is that her sugars behave differently (in fact, the opposite) from what she would expect. She is confused. She started taking her diabetes seriously two years ago, after her control had been quite bad. Recently she was getting back on track, by bringing down her sugar levels, She was getting to know her body and how it would react according to what she did (food, activity, stress, excitement...). However, this week things are completely different, nothing makes sense anymore and she cannot predict. The scary part, she says, is that she has no idea anymore of what her body is doing, it is a stranger to her.

Of the 20 students at the camp, four boys were the 'the sorted boys'. Of similar age as the other students (16,17), they seemed older. This apparent age difference came from the fact that these boys were mature, well-educated, sporty, not rebellious teenagers. They were also sorted about their diabetes. They all had happy homes and a good education, which is more than the average students could hope for. 17-year-old Michael might well have been a volunteer helping out at the camp. During late evening, when the students would be lounging about, chatting and drinking, Michael would ask some whether they had eaten enough, he would make them tea and toast, with lots of butter and jam. One boy in particular, who drank a lot of alcohol and had a tendency to have hypos later at night, was challenged by Michael into a bread eating competition (eating bread would feed the boy carbohydrates, preventing a possible hypo in the night). All of them being bright and fit, these 'sorted' boys could have easily distanced themselves from the other, slouchy and rough students. However, they were concerned and engaged with the others and by performing their normal routine, showed how it was OK to take care of diabetes. Probably helped by their good looks and fitness, they could do this without being seen as nerdy or fussy by the others. The four sorted boys, knowing why they were there and enjoying all the sports, were a crucial presence at the camp. Their positive attitude rubbed off on the others.

A good example is the last day's morning discussion, when the young people were confronted with practical diabetes issues. Faced with questions like 'what are some of the complications you can get from diabetes?', students would answer: 'what are complications?'. Staff would then explain: 'like something with your eyes, your kidneys…', students: 'I don't know, I don't know what happens to your eyes, does something happen to your kidneys?' When other students were asked to explain and show how a blood test worked and said they didn't want to, Phil and Stan went to get their blood sugar meter and did a test. When asked to explain about injections, Chris got up to get his pen and did an injection there in front of all of us, then Phil took over and explained the different parts of a syringe or pen and how to do things. They made it fun: "all right: this is how you do it, first this part goes…" all were listening and Phil and Chris made some sort of stand-up duo act of it. Here were young people with diabetes explaining to others how things worked. No 'boring talk' by a 'patronizing nurse' or doctor, which health carers are so wary about, just two tall, fit and admired boys doing their thing. It worked.

Jo (15) who has been to other 'strict' diabetes camps, tells me he knew that this one wouldn't be strict "because we are old enough now." Sales rep Jessica of the company that has sponsored the camp for 18 years confirms this. "The idea behind this camp is, this camp is not disciplined, because they are old enough. So no interfering from our [staff, health carers] part. It is all about experimenting for themselves and finding out. So, it is different from other camps where they take their insulin together and teach new techniques and places to give injections and test at certain times. We always tell them 'it's your diabetes, not ours'."

Later at another diabetes camp for 8 year olds I will talk to Paul, a 32 year old with diabetes, and enthusiastic volunteer in diabetes activities and parent groups. He attended Pinewood as a student in 1990; The 'disaster year' he calls it, since that was the camp a girl tried to commit suicide. He says the camp was 'a big eye-opener' for him. "I saw all those people doing things I didn't know you could do with diabetes. I was very strict, with diet and such, and here were all these young people drinking alcohol and eating everything. So I saw you could still eat chocolate and sugar". When I ask [*patronizingly*] that he then saw he could do what he couldn't do, he corrects me. "I wouldn't call it 'what you shouldn't do'. It's good to be able to do these things". Would he have liked a bit more diabetes education at the camp?

"No, 'cause by that age you know most of what you should know and that's also not how the camp works. They just let people get on with things."

*

The log cabin: 30 strangers stuck on Noah's Ark. After some days a symbiosis: a growing towards each other of people who did not know each other, who don't have anything in common apart from (their age and) diabetes. It is really the young people who take care of each other. The health carers are there for the emergencies or nightly hypos, during the daytime the students more or less sort out each other.

A liminal phase. Taken out of their daily lives, away from friends and family, jumbled together with strangers, however, strangers who share a vital part of their lives: diabetes. The students get the space and time to experience something new, eye opening and strengthening. They can see themselves in a different light and even be surprised: 'I actually enjoy being outside', 'I enjoy doing exercise and being tired afterwards'. The students experience other teenagers with the same chronic illness, while they have often

felt quite alone with it over the years. For a week they don't have to be cautious, in case they would faint with a hypo, people would know what was going on and take care of them. They know they're all in the same boat.

Living in this place in the middle of nowhere for a week, with people we never met before and might not meet again is disorientating. It is also what makes this experience so powerful. It will remain ingrained in our memories, not to be trivialised or turned sour by future events. It will always be '8 days in Pinewood.' a moment we shared, undisturbed by every day details. We all feel we need a serious debriefing before we can leave this cocoon and go out to face the world again. When on Friday morning the bus leaves to the station, all mobile phones hold 20 extra numbers in their memory.

***

Appendix 2

Type 1 Diabetes[1]

Type 1 diabetes occurs when the body's own immune system destroys the insulin-producing cells of the pancreas. Normally, the body's immune system fights off foreign invaders like viruses or bacteria. But for unknown reasons, in people with type 1 diabetes, the immune system attacks various cells in the body. This results in a complete deficiency of the insulin hormone.

1. Understanding Insulin

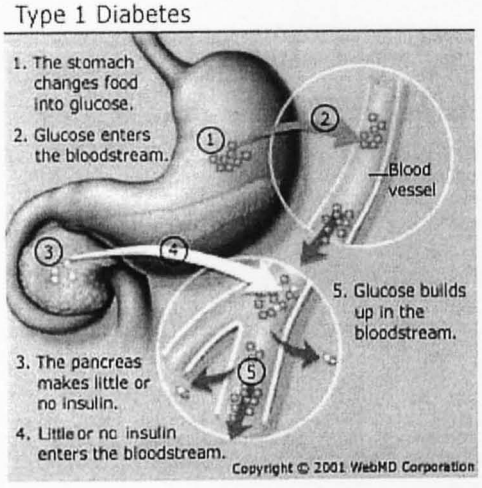
Normally the hormone insulin is secreted by the pancreas in low amounts. When you eat a meal, glucose (sugar) from food stimulates the pancreas to release insulin. The amount that is released is proportional to the amount that is required by the size of that particular meal.

Insulin's main role is to help move certain nutrients -- especially glucose -- into the cells of the body's tissues. Cells use sugars and other nutrients from meals as a source of energy to function.

The amount of sugar in the blood decreases once glucose enters the cells. Normally that signals the beta cells in the pancreas to lower the amount of insulin secreted so that you don't develop low blood sugar levels (hypoglycemia). But the destruction of the beta cells that occurs with type 1 diabetes throws the entire process into disarray.

[1] This information is taken, in changed format, from www.webmd.com.

Type 1 Diabetes



In people with type 1 diabetes, glucose isn't moved into the cells because insulin is not available. When glucose builds up in the blood instead of going into cells, the body's cells starve for nutrients and other systems in the body must provide energy for many important bodily functions. As a result, high blood glucose develops and can cause:

- Dehydration

  The build up of sugar in the blood can cause an increase in urination (to try to clear the sugar from the body). When the kidneys lose the glucose through the urine, a large amount of water is also lost, causing dehydration.

- Weight loss

  The loss of sugar in the urine means a loss of calories which provide energy and therefore many people with high sugars lose weight. (Dehydration also contributes to weight loss.)

- Diabetic ketoacidosis (DKA)

  Without insulin and because the cells are starved of energy, the body breaks down fat cells. Products of this fat breakdown include acidic chemicals called ketones that can be used for energy. Levels of these ketones begin to build up in the blood, causing an increased acidity. The liver continues to release the sugar it stores to help out. Since the body cannot use these sugars without insulin, more sugars piles into the blood stream. The combination of high excess sugars, dehydration and acid

build up is known as "ketoacidosis" and can be life-threatening if not treated immediately.

- Damage to the body

  Over time, the high glucose levels in the blood may damage the nerves and small blood vessels of the eyes, kidneys, and heart and predispose a person to atherosclerosis (hardening) of the large arteries that can cause heart attack and stroke.

2. How Is Type 1 Diabetes Managed?

Many people with type 1 diabetes live long, healthy lives. The key to good health is keeping your blood sugar levels within your target range, which can be done with meal planning, exercise and intensive insulin therapy. All people with type 1 diabetes must use insulin injections to control their blood glucose. You will also need to check your blood sugar levels regularly and make adjustment of insulin, food and activities to maintain a normal sugar.

3. Consequences of Uncontrolled Diabetes

When diabetes isn't well controlled, a number of serious or life-threatening problems may develop, including:

- Retinopathy

  This eye problem occurs in 75% to 95% of adults who have had diabetes for more than 15 years. Diabetic retinopathy in type 1 diabetes is extremely rare before puberty no matter how long they have had the disease. Medical conditions such as good control of sugars, management of hypertension and regulation of blood lipids are important to prevent retinopathy. Fortunately, the vision loss isn't significant in most people with the condition.

- Kidney damage

  About 35% to 45% of people with type 1 diabetes develop kidney damage, a condition called nephropathy. The risk for kidney disease increases over time and becomes evident 15 to 25 years after the onset of the disease. This complication carries significant risk of serious illness -- such as kidney failure and heart disease.

- Poor blood circulation.

  Damage to nerves and hardening of the arteries leads to decreased sensation and poor blood circulation in the feet. This can lead to increased risk of injury and decreased ability to heal open sores and wounds, which in turn significantly raises the risk of amputation. Damage to nerves may also lead to digestive problems such as nausea, vomiting and diarrhea.

*

Glossary[1]

Type 1 Diabetes	Occurs when the body's own immune system destroys the insulin-producing cells of the pancreas. (See Appendix 2 for more information on the mechanics and consequences of Type 1 diabetes.)
DKA	Diabetic ketoacidosis: a dangerous condition that is caused by very high blood sugar levels.
HbA1c	Glycosylated Haemoglobin. In daily use it is called and pronounced 'H-b-A-one-c'.
HbA1c test	Lab test that shows the average amount of blood sugars in the blood over the last two to three months. The test shows if a person's blood sugar is close to normal or too high. It is the best test for a health care provider to tell if a person's blood sugar is under control.
Hyperglycaemia	High blood sugars. Develops when there is too much sugar in the blood. When a person with diabetes has hyperglycemia frequently or for long periods of time as indicated by a high HbA1c blood test, damage to nerves, blood vessels and other body organs can occur. It can also lead to DKA.
Hypoglycaemia	Low blood sugar. Occurs when the level of sugar, or glucose, in the blood drops too low to fuel the body. This can be caused by too much insulin in the blood.
Insulin	Hormone produced in the pancreas that allows sugar (glucose) to enter body cells, where it is used for energy. It also helps the body store extra sugar in muscle, fat, and liver cells where it can be released and used for energy when needed. Diabetes develops if the body does not produce enough insulin or does not use insulin properly. (See Appendix 2 for information on how insulin works in the body.)
Ketones	Substances produced by the body as it breaks down fats for energy, a process called ketosis. High blood levels of ketones may cause fruity-smelling breath, loss of appetite, nausea or vomiting, and fast, deep breathing. In severe cases, it may lead to coma and death.

[1] Descriptions taken from www.webmd.com and www.diabetestoolbox.com.

Bibliography

Ariès, P. 1962. *Centuries of childhood.* London: Jonathan Cape.

Artificial intelligence. Body repair: the ultimate guide. In *The Scotsman*, 7/11/02.

Baier, A. 1994. *Moral Prejudices. Essays on Ethics.* Cambridge: Harvard University Press.

Bechhofer, F. 2004. Consumption, Lifestyle and Culture. In L. Paterson, F. Bechhofer and D. McCrone *Living in Scotland. Social and economic change since 1980.* Edinburgh: Edinburgh University Press.

Benthall, J. 1992. A late developer? The ethnography of children. *Anthropology Today* **8** (2), 1.

Brown, G. 1983. Introduction. In G. Brown and R. Cook (eds) *Scotland. The real divide. Poverty and deprivation in Scotland.* Edinburgh: Mainstream Publishing.

Budd, S. & Sharma, U. 1994. Introduction. In S. Budd and U. Sharma (eds) *The healing bond.* London: Routledge.

Canguilhem, G. 1992. Machine and organism. In *Incorporations* (eds) J. Crary & S. Kwinter. New York: MIT Press.

Crapanzano, V. 2004. *Imaginative horizons: an essay in literary-philosophical anthropology.* Chicago: The University of Chicago Press.

Crapanzano, V. 1980. *Tuhami. Portrait of a Moroccan.* Chicago: University of Chicago Press.

Csordas, T. 2000. The body's career in anthropology. In H. Moore (ed.) *Anthropological theory today.* Cambridge: Polity Press.

Csordas, T. 1994. Introduction: the body as representation and being-in-the-world. In T. Csordas (ed.) *Embodiment and experience. The existential ground of culture and self.* Cambridge: Cambridge University Press.

Csordas, T. 1993. Somatic modes of attention. *Cultural Anthropology* **8** (2), 135-156.

Dickson, T. 1989. Scotland is different, OK? In D. McCrone, S. Kendrick & P. Straw (eds) *The Making of Scotland: nation, culture and social change.* Edinburgh: Edinburgh University Press.

Dickson, T and Treble, J. 1992. *People and society in Scotland. Vol III 1914-1990.* Edinburgh: John Donald Publishers.

Douglas, M. 1970. The two bodies. In M. Douglas, *Natural Symbols*. London: The Cresset Press.

Downey, G. & Dumit, J. 1997. Locating and intervening. An Introduction. In G. Downey and J. Dumit (eds) *Cyborgs and citadels. Anthropological interventions in emerging sciences and technologies*. Santa Fe: School of American Research Press.

Downey, G. 1995. Human agency in CAD-CAM technology. In C. Gray (ed.) *The Cyborg handbook.* New York: Routledge.

Downey,G., Dumit, J. and Willimas, S. 1995. Cyborg anthropology. In C. Gray (ed.) *The Cyborg handbook.* New York: Routledge.

Dumit, J. 1995. Twenty-first-century PET: looking for mind and morality through the eye of technology. In G. Marcus (ed.) *Technoscientific Imaginaries.* Chicago: University of Chicago Press.

Escobar, A. 1994. Welcome to Cyberia. Notes on the anthropology of cyberculture. *Current Anthropology* **35** (3), 211-231.

Foucault, M. 1979. *Discipline and punish. The birth of the clinic.* New York : Vintage Books.

Franklin, S. 1997. *Embodied progress. A cultural account of assisted conception.* London: Routledge.

Franklin, S. 1995. Science as culture, cultures of science. *Annual review of Anthropology* **24**, 163-184.

Good, B. 1994. *Medicine, rationality and experience. An anthropological perspective.* Cambridge: Cambridge University Press.

Goodin, R. 1997 Permissible paternalism: saving smokers from themselves. In H. Lafollette (ed.) *Ethics in Practice: an anthology.* Oxford: Blackwell.

Gray, C. (ed.) 1995. *The cyborg handbook.* New York: Routledge.

Greene, A. 2000. *Health carers' and young people's conceptualizations of chronic illness: an anthropological interpretation of 'Diabetes mellitus'.* Unpublished Ph.D. thesis, St Andrews University.

Hammond, M., Howard J. & Keat, R. 1991. *Understanding Phenomenology.* Oxford: Basil Blackwell.

Haraway, D. 1997. Mice into wormholes. A comment on the nature of no nature. In G. Downey and J. Dumit (eds) *Cyborgs and Citadels. Anthropological interventions in emerging sciences and technologies*. Santa Fe: School of American Research Press.

Haraway, D. 1995. Cyborgs and symbionts. In C. Gray (ed.) *The cyborg handbook*. New York: Routledge.

Haraway, D. 1991. *Simians, cyborgs and women: the reinvention of nature*. New York: Routledge.

Haraway, D. 1985. A manifesto for cyborgs: science, technology, and socialist feminism in the 1980s. *Socialist Review* **80**, 65-108.

Harbers, H., Mol, A. & Stollmeyer, A. 2002. Food matters. Arguments for an ethnography of daily care. *Theory, Culture and Society* **19**, 5/6, 207-226.

Hardman, C. 1973. Can there be an anthropology of children? *Journal of the anthropology society of Oxford* **4** (1), 85-99.

Hardy, A. 2001. A Golden Age? 1945-2000. In A. Hardy *Health and Medicine in Britain since 1860*. Hampshire: Palgrave.

Heath, C., Luff, P. & Svensson, M. 2003. Technology and medical practice. *Sociology of Health and Illness* **25**, 75-96.

Heidegger, M. 1977. *The question concerning technology*. Transl. W. Lovitt. New York: Harper & Row.

Hirsch, E. 1992. The long term and the short term of domestic consumption. An ethnographic case study. In R. Silverstone and E. Hirsch (eds) *Consuming technologies. Media and information in domestic spaces*. London: Routledge.

Hubley, J. 1987. Poverty and health. In G. Brown and R. Cook (eds) *Scotland. The real divide. Poverty and deprivation in Scotland*. Edinburgh: Mainstream Publishing.

Hutchby, I. & Moran-Ellis, J. 1998. Situating children's social competence. In I. Hutchby & J. Moran-Ellis (eds) *Children and social competence: arenas of action*. London: The Falmer Press.

Ihde, D. 1979. *Technics and praxis*. Dordrecht: D. Reidel.

Ingold, T. 1993. Tool-use, sociality and intelligence. In K. Gibson & T. Ingold (eds) *Tools, language and cognition in human evolution*. Cambridge: Cambridge University Press.

Jackson, J. 1994. Chronic pain and the tension between the body as subject and object. In T. Csordas (ed.) *Embodiment and experience. The existential ground of culture and self*. Cambridge: Cambridge University Press.

Jackson, M. 2002a. *The politics of storytelling. Violence, transgression and intersubjectivity*. Copenhagen: Museum Tusculanum Press.

Jackson, M. 2002b. Familiar and foreign bodies: a phenomenological exploration of the human-technology interface. *Journal of the Royal Anthropological Institute* **8** (2), 333-345.

Jackson, M. 1998. Introduction. *Minima Ethnographica. Intersubjectivity and the anthropological project*. Chicago: University of Chicago Press.

Jackson, M. 1995. Epilogue. In M. Jackson *At home in the world*. Durham: Duke University Press.

Jackson, M. 1996. Introduction. Phenomenology, radical empiricism, and anthropological critique. In M. Jackson (ed.) *Things as they are. New directions in phenomenological anthropology*. Bloomington: Indiana University Press.

Jackson, M. 1989. Knowledge of the body. In M. Jackson *Paths toward a clearing. Radical empiricism and ethnographic inquiry*. Bloomington: Indiana University Press.

James, A. 2002. The English child: toward a cultural politics of childhood identities. In N. Rapport (ed) *British Subjects: an anthropology of Britain*. Oxford: Berg.

James, A. 1986. Learning to belong: the boundaries of adolescence. In A. Cohen (ed) *Symbolising boundaries. Identity and Diversity in British Cultures*. Manchester: Manchester University Press.

James, A., Jenks, C. & Prout, A. 1998. *Theorizing childhood*. Cambridge: Polity Press.

Jenks, C. 1996. *Childhood*. London: Routledge.

Kaplan, R. et al 1993. *Health and human behavior*. New York: McGraw-Hill.

Kaufman, S. 1988. Toward a phenomenology of boundaries in medicine: chronic illness experience in the case of stroke. *Medical Anthropology Quarterly* 338- 354.

Kelly, M. & Field, D. 1996. Medical sociology, chronic illness and the body. *Sociology of Health and Illness* **18** (2), 241-257.

Kleinman, A. & Kleinman, J. 1996. Suffering and its professional transformation. Toward an ethnography of interpersonal experience. In M. Jackson (ed.) *Things as they are. New directions in phenomenological anthropology*. Bloomington: Indiana University Press.

Kleinman, A. 1995. *Writing at the margin. Discourse between anthropology and medicine*. Berkeley: University of California Press.

Knox, W. 1999. *Industrial nation. Work, culture and society in Scotland, 1800 – Present*. Edinburgh: Edinburgh University Press.

Kohrman, A. 1994. Chimeras and odysseys. Towards understanding the technology-dependent child. Special Supplement *Hastings Centre Report* **24** (5) S4-S6.

Latour, B. 1993. *We have never been modern*. London: Harvester Wheatsheaf.

Latour, B. 1992. Where are the missing masses? The sociology of a few mundane artefacts. In *Shaping technology/Building society: studies in sociotechnical change*. W. Bijker & J. Law (eds). Cambridge, Mass: MIT Press.

Law, J. n.d. *Networks, relations, cyborgs: on the social study of technology*. (draft). Published by the Centre for Science Studies and the Department of Sociology, Lancaster University, at: http://www.comp.lancs.ac.uk/sociology/soc042jl.html.

Law, J. & Hassard, J. (eds) 1999. *Actor network theory and after*. Oxford: Blackwell Publishers.

Law, J. & Mol, A. n.d. *Situating technoscience: an inquiry into spatialities*. (draft) . Published by the Centre for Science Studies and the Department of Sociology, Lancaster University, and the Department of philosophy, the University of Twente, at: http://www.comp.lancs.ac.uk/sociology/soc052jl.html.

Law, J. & Moser, I. 2001. Cyborg. In *International Encyclopedia of the social and behavioural sciences*. 3202-3204. Amsterdam: Elsevier.

Law, J. & Moser, I. 1999. *Managing, subjectivities and desires*. Published by The Centre for Science Studies and the Department of Sociology, Lancaster University and Teknologi, Innovasjon og Kultur, Oslo University at: http://www.comp.lancs.ac.uk/sociology/soc019jl.html.

Law, J. & Singleton, V. 2000. Performing technology's stories. *Technology and Culture* **41**, 765-775.

Leder, D. 1992. Introduction. In D. Leder (ed.) *The body in medical thought and practice*. Dordrecht: Kluwer Academic Publishers.

Leder, D. 1992. A tale of two bodies: the Cartesian corpse and the lived body. In D. Leder (ed.) *The body in medical thought and practice*. Dordrecht: Kluwer Academic Publishers.

Leder, D. 1990. *The absent body*. Chicago: University of Chicago Press.

Lock, M., Young, A. & Cambrosio, A. 2000. *Living and working with the new medical technologies: intersections of inquiry*. Cambridge: Cambridge University Press.

Lock, M. 1993. Cultivating the body: anthropology and epistemologies of bodily practice and knowledge. *Annual Review of Anthropology* **22**, 133-155.

Lock, M. & Scheper-Hughes, N. 1996. A critical-interpretive approach in medical anthropology: rituals and routines of discipline and dissent. In C. Sargent & T. Johnson (eds) *Medical Anthropology*. Westport: Praeger Publishers.

McCrone, D. 2004a. Population and Demography. In L. Paterson, F. Bechhofer and D. McCrone *Living in Scotland. Social and economic change since 1980.* Edinburgh: Edinburgh University Press.

McCrone, D. 2004b. Families and Households. In L. Paterson, F. Bechhofer and D. McCrone *Living in Scotland: social and economic change since 1980.* Edinburgh: Edinburgh University Press.

McGuiness, B. 1988. *Wittgenstein: a life (young Ludwig, 1889-1921).* Berkeley: University of California Press.

McIntyre, A. 1984. *After virtue: a study in moral theory.* Indiana: University of Notre Dame Press.

Meløe, J. 1988. Some remarks on agent perception. In L. Hèrtzberg & J. Pietarinen (eds) *Perspectives on human conduct.* ET Brill Publisher.

Meløe, J. n.d. *The two landscapes of Northern Norway.*

Meløe, J. n.d. *Remaking a form of life.*

Meløe, J. n.d. *Words and objects.*

Merleau-Ponty, M. 1962. *Phenomenology of perception.* Transl. C. Smith. London: Routledge & Kegan Paul.

Mintz, S. 1985. *Sweetness and power: The place of sugar in modern history.* New York: Penguin Books.

Mol, A. 2002. *The body multiple: ontology in medical practice.* Durham: Duke University Press.

Mol, A. 2002. *De Burger en het lichaam. Politiek-theoretische verkenningen.* Socrates lezing. Published at http://www.human.nl/hkc/socrates/2002.htm.

Mol, A. & Elsman, B. 1996. Detecting disease and designing treatment. Duplex and the diagnosis of diseased leg vessels. *Sociology of Health and Illness* **18** (5), 609-603.

Mol, A. & Law, J. 1999. *Situated bodies and distributed selves: enacting hypoglycaemia.* (draft) published by the Department of Sociology, Lancaster University at: http://www.lancaster.ac.uk/sociology/stslaw5.html.

Nicolson, M. 1993. Medicine. In P. Scott (ed) *Scotland. A concise cultural history.* Edinburgh: Mainstream Publishing Company.

Noddings, N. 1984. *Caring: a feminine approach to ethics and moral education.* Berkeley: University of California Press.

Moss, D. 1992. Obesity, objectification and identity: the encounter with the body as an object in obesity. In D. Leder (ed.) *The body in medical thought and practice.* Dordrecht: Kluwer Academic Publishers.

Overing, J. 1996. *Under the sky of the domesticated.* Inaugural lecture, St Andrews University. Unpublished.

Paterson, L, Bechhofer, F. and McCrone, D. 2004. *Living in Scotland. Social and economic change since 1980.* Edinburgh: Edinburgh University Press.

Pfaffenberger, B. 2001 Anthropology of technology.. In *International encyclopedia of the social and behavioural sciences.* 15515-15521. Amsterdam: Elsevier.

Pfaffenberger, B. 1992. Social anthropology of technology. *Annual review of Anthropology* **21**, 491-516.

Prout, A. 1996. Actor-network theory, technology and medical sociology: an illustrative analysis of the metered dose inhaler. *Sociology of Health and Illness* **18** (2), 198-219.

Purves, L. 2003. What we can do about the hell of being 16. *The Times* 9 December 2003.

Rabinow, P. 1997. Science as a practice. The higher indifference and mediated curiosity. In G. Downey and J. Dumit (eds) *Cyborgs and Citadels. Anthropological interventions in emerging sciences and technologies.* Santa Fe: School of American Research Press.

Rapp, R. 1997. Real-time fetus. The rile of the sonogram in the age of monitored reproduction. In G. Downey and J. Dumit (eds) *Cyborgs and Citadels. Anthropological interventions in emerging sciences and technologies.* Santa Fe: School of American Research Press.

Rapport, N. 2003. *I am dynamite. An alternative anthropology of power.* London: Routledge.

Rapport, N. 2001. Towards a post-cultural anthropology of personally embodied knowledge. *Social Anthropology* **9** (1), 95-102.

Rapport, N. 1999. Context as an act of personal externalisation. In R. Dilley (ed.)*The problem of context.* Oxford: Berghahn.

Sargent, C. & Johnson, T. 1996. Introduction. In C. Sargent & T. Johnson (eds) *Medical anthropology.* Westport: Praeger Publishers.

Sartre, J-P. 1992. Intentionality. In *Incorporations* (eds) J. Crary & S. Kwinter. New York: MIT Press.

Scheper-Hughes, N. 1992. *Death without weeping. The violence of everyday life in Brazil.* London: University of California Press.

Scheper-Hughes, N. 1990. Three propositions for a critically applied medical anthropology. *Social Science and Medicine* **30** (2), 189-197.

Schlecker, M. & Hirsch, E. 2001. Incomplete knowledge: ethnography and the crisis of context in studies of media, science and technology. *History of the Human Sciences* **14** (1), 69-87.

Scott, P. 1993. Introduction. In P. Scott (ed) *Scotland: A concise cultural history.* Edinburgh: Mainstream Publishing Company.

Shanon, B. 1993. *The representational and the presentational. An essay on cognition and the study of mind.* London: Harvester Wheatsheaf.

Sharp, L. 2000. The commodification of the body and its parts. *Annual Review of Anthropology* **29**, 287-328.

Silverstone, R. & Hirsch E. 1992. Introduction. In R. Silverstone and E. Hirsch (eds) *Consuming technologies. Media and information in domestic spaces.* London: Routledge.

Strathern, M. 1992. *Reproducing the future: essays on anthropology, kinship and the new reproductive technologies.* Manchester: Manchester University Press.

Strathern, M. 1992. Foreword: the mirror of technology. In R. Silverstone and E. Hirsch (eds) *Consuming technologies. Media and information in domestic spaces.* London: Routledge.

Strathern, M. 1991. *Partial connections.* Savage: Rowman and Littlefield Publishers.

Strathern, A. & Lambek, M. 1998. Introduction. Embodying sociality: Africanist-Melanesianist comparisons. In M. Lambek & A. Strathern (eds) *Bodies and persons. Comparative perspectives from Africa and Melanesia.* Cambridge: Cambridge University Press.

Suchman, L. n.d. Human/machine reconsidered. Published by the Department of Sociology, Lancaster University at: http://www.comp.lancs.ac.uk/sociology/soc040ls.html.

Taylor, C. 1985. *Philosophy and the human sciences. Philosophical papers II.* Cambridge: Cambridge University Press.

Timmermans, S. 1998. Resuscitation technology in the emergency department: towards a dignified death. *Sociology of Health and Illness* **20** (2), 144-167.

Timmermans, S. 2001. Health care technology. In *International encyclopedia of the social and behavioural sciences.* 6544-6550. Amsterdam: Elsevier.

Timmermans, S. & Berg, M. 2003. The practice of medical technology. *Sociology of Health and Illness* **25**, 97-114.

Whitehead, M. 1992. *The Health Divide.* London: Penguin Books.

Willems, D. 1998. Inhaling drugs and making worlds: a proliferation of lungs and asthma. In A. Mol & M. Berg (eds) *Differences in medicine.* London: Duke University Press.

Williams, S. 1996. Medical sociology, chronic illness and the body: a rejoinder to Michael Kelly and David Field. *Sociology of Health and Illness* **18** (5), 699-709.

Young, A. 1982. The anthropologies of illness and sickness. *Annual Review of Anthropology* **11**, 257-285.

Young, K. 1997. *Presence in the flesh.* Cambridge: Harvard University Press.

Medical Literature

Anderson, B. et al 1999. An office-based intervention to maintain parent-adolescent teamwork in diabetes management. *Diabetes Care* **22** (5), 713-721.

Anderson, R. and Funnell, M. 2000. Compliance and Adherence. *Diabetes Education* **26**: 597-604.

Anderson, R. 1995. Patient empowerment and the traditional medical model. *Diabetes Care* **18** (3), 412-415.

Boland, E. et al 1999. Continuous Subcutaneous Insulin Infusion. A new way to lower risk of severe hypoglycemia, improve metabolic control, and enhance coping in adolescents with type 1 diabetes. *Diabetes Care* **22** (11),1779-1784.

Brown, F. 1996. Counselling for Patient Empowerment. *Practical Diabetes International* **13** (6), 189-190.

Brown, F. 1997. Patient Empowerment through Education. *Professional Nurse Study Supplement* **13** (3), S4-S6.

Clement, S 1995. Diabetes Self-Management Education. *Diabetes Care* **18** (8), 1204-1214.

Danne, T, Mortensen, H, Hougaard, P et al 2001. Persistent differences among centres over 3 years in glycemic control and hypoglycemia in a study of 3805 children and adolescents with type 1 diabetes from the Hvidøre study group. *Diabetes Care* **24** (8), 1342-1347.

Department of Health 2001. *The Expert Patient. A new approach to chronic disease management for the 21st Century.*

Diabetes Control and Complications Trial Research Group (DCCT) 1995. Implementation of treatment protocols in the Diabetes Control and Complications Trial. *Diabetes Care* **18** (3), 361-376.

Funnell, M., Anderson, R. et al. 1991. Empowerment: an idea whose time has come in diabetes education. *The Diabetes Educator* **17**: 37-41.

Greene, S. 1996. Diabetes in the Young: current challenges in their management. *Clinical Paediatrics* **4** (4), 563-575.

Hampson, S., Skinner, C. et al. 2000. Behavioural interventions for adolescents with type 1 diabetes. How effective are they? *Diabetes Care* **23** (9), 1416-1422.

Hoey, H., Aanstoot, H, Chiarelli, F. et al 2001. Good metabolic control is associated with better quality of life in 2101 adolescents with type 1 diabetes. *Diabetes Care* **24** (11), 1923-1928.

International Society for Pediatric and Adolescent Diabetes (ISPAD) 2000. *Consensus Guidelines 2000. ISPAD Consensus guidelines for the management of type 1 diabetes mellitus in children and adolescents.* Medical Forum International: Zeist.

Joffe, S. et al 2003. What do patients value in their hospital care? An empirical perspective on autonomy centred bioethics. *Journal of Medical Ethics* **29**, 103-108.

Keen, H, Pickup, J. et al 2001. New horizons in insulin pump therapy 2001. *Practical Diabetes* **18** (5) Supplement.

Knight, K., Bundy, C., Morris, R. e.a. 2003. The effects of group motivational interviewing and externalizing conversations for adolescents with Type-1 diabetes. *Psychology, Health and Medicine*, **8** (2), 149-157.

Meijer, S., Sinnema, G., Bijstra, J. e.a. 2002. Coping style and locus of control as predictors for psychological adjustment of adolescents with a chronic illness. *Social Science and Medicine* **54**, 1453-1461.

Morris, A., Greene, S. et al 1997. Adherence to insulin treatment, glycaemic control and ketoacidosis in insulin-dependent diabetes mellitus. *The Lancet* **350**, 1505-1510.

Mortensen, H., Robertson, K., Aanstoot, H. et al 1998. Insulin management and metabolic control of type 1 diabetes mellitus in childhood and adolescence in 18 countries. *Diabetic Medicine* **15**, 752-759.

Mortensen, H. & Hougaard, P. 1997. Comparison of Metabolic Control in a Cross-Sectional Study of 2873 Children and Adolescents With IDDM from 18 Countries. *Diabetes Care* **20** (5), 714-720.

Newton, R., Connacher, A., Morris, A. et al 2000. Dilemmas and directions in the care of the diabetic teenager: the Arnold Bloom Lecture 1999. *Practical Diabetes* **17** (1), 15-20.

Pickup, J. & Keen, H. 2002. Continuous subcutaneous insulin infusion at 25 years. *Diabetes Care* **25** (3), 593-598.

Pickup, J et al 1981. Patient reactions to long-term outpatient treatment with continuous subcutaneous insulin infusion. *British Medical Journal* **282**,766-768.

Schade, D. & Valentine, V. 2002. To pump or not to pump. *Diabetes Care* **25** (11), 2100-2101.

Scottish Executive Health Department 2001. *Scottish Diabetes Framework.*

Scottish Study Group for the Care of the Young Diabetic (SSGCYD) 2001. Factors influencing glycaemic control in young people with type 1 diabetes in Scotland. *Diabetes Care* **24** (2), 239-244.

Shucksmith, J & Spratt, J. 2003. Young people's self-identified health needs. *Scottish Youth Issues Journal* **6**, 47-59.

Skinner, C., Channon, S., Howells, L. et al 2000. Diabetes during adolescence. In F. Snoek & C. Skinner (eds) *Psychology in diabetes care.* John Wiley & Sons: Chichester.

Thorn, S., Paterson, B. & Russell, C. 2003. The structure of everyday self-care decision making in chronic illness. *Qualitative Health Research* **13** (10), 1337-1352.

Williams, G., Freedman, Z. et al 1998. Supporting Autonomy to Motivate Patients with Diabetes for Glucose Control. *Diabetes Care* **21** (10), 1644-1651.

Wolpert, H. & Anderson, B. 2001. Young adults with diabetes. Need for a new treatment paradigm. *Diabetes Care* **24** (9), 1513- 1514.

*